# Functional Recovery after Brain Injury Rehabilitation

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# Declaration

I declare that the research and composition of this thesis is my own work. However, I acknowledge the following people for their contribution:

Sarah Cudmore for carrying out the independent assessment of patients during the intervention phase of the study.

Alister Berry, Sarah Cudmore, Brian Pentland and Robin Prescott as co-authors of publications referred to within the text.

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# Glossary

This is not a complete glossary, but is intended to be a guide to those abbreviations used frequently throughout the text.

| Abbreviation / Term | Explanation |
|---|---|
| ERSS | Edinburgh Rehabilitation Status Scale |
| Factor Analysis | Analysis to explore whether certain items of a scale might logically be expressed as one item or factor |
| FIM | Functional Independence Measure |
| FIM+FAM | Functional Assessment Measure (incorporating the FIM) |
| GCS | Glasgow Coma Score |
| GOS | Glasgow Outcome Scale |
| HBI | Haemorrhagic Brain Injury |
| IQR | Interquartile range (a measure of dispersion of data more appropriate than exploring the standard deviation in ordinal data as it is not effected as greatly by outlying values) |
| Logistic Regression | A robust form of analysis which can be used to explore whether certain variables might predict membership of a dichotomous variable |
| LOS | Length of Stay |
| OPCS | Office of Population, Censuses and Surveys Scales of Disability |
| PTA | Post Traumatic Amnesia |
| RQ | The Relative Questionnaire |
| SF-36 | Short Form 36 Questionnaire |
| TBI | Traumatic Brain Injury |
| Wald | The test statistic in logistic regression which influences the removal of variables from the regression equation |

# Abstract

There is a growing consensus that brain injury results in a wide range of physical, social and psychological sequelae which can impinge on the lives of both the survivor and his or her family for many years. However, our knowledge of the natural course of recovery and the impact of rehabilitation interventions remains inadequate. One reason for this has been the lack of adequate measures of the functional consequences that effect the individual on a day to day basis.

The need to develop measures pertinent to the desired outcomes in rehabilitation has led to an ever increasing number of tools becoming available in the last decade. However, most research still focuses on the early neurosurgical and neurological consequences with long-term sequelae of brain injury predominately defined in terms of neuropsychological deficits. Until this decade there has been a dearth of research into the functional consequences of such impairments despite increasing awareness that for the individual and family, day to day functioning is of major concern. The thesis therefore has two main goals.

Firstly:- a descriptive study explored functional status in patients after brain injury following discharge from inpatient rehabilitation to their own homes in the community.

Secondly:- an intervention study was carried out to explore the role of home based visits as part of post discharge follow-up of patients after inpatient rehabilitation to address the findings of the first study.

In the first study, 89 patients admitted consecutively for early inpatient rehabilitation following a traumatic or haemorrhagic brain injury were visited at home by the researcher at six weeks after discharge and again at 14 months. Assessment using a number of measures of function characterised the disabilities that the patients experienced and revealed that deterioration in everyday function was common after discharge home. Further, the majority of carers were noted to request information and advice on a range of subjects.

These two factors led to the intervention study where 43 patients were recruited to evaluate whether visits to the patient's home in the early weeks after discharge would prevent deterioration and satisfy carers' requests for information and support. Randomisation using the minimisation method led to and experimental group with 22 subjects and a control group of 21. Patients in the experimental group were visited weekly until the sixth week when both groups were assessed using a wide range of functional measures. Both groups were also assessed at 15 months after injury. The experimental group deteriorated less than the control group in the early post-discharge period and patients, carers and professionals valued the service provided. However, this functional improvement was not maintained at the 15 month follow-up in some cases and factors contributing to this are discussed.

This study explores and evaluates measures of function after brain injury rehabilitation, hopefully contributing to a better understanding of the complex nature of disability in that group. The implications for service provision and limitations and constraints in rehabilitation for this population are discussed.

CHAPTER 1

# DISABILITY AND FUNCTIONAL OUTCOME AFTER BRAIN INJURY - WHAT HAPPENS AFTER INPATIENT REHABILITATION?

## 1.1 Introduction

The brain is the centre of human invention, intellect and emotion. It co-ordinates all that we do as human beings to pursue functions that give meaning to our lives. Our activities, relationships and even apparently simple thoughts are only possible due to constant manipulation of complex information by the brain. Research has highlighted that even slight brain damage, as in the case of a relatively minor head injury (Alexander, 1995), may result in disabling consequences for the individual and their family persisting over many years. The effects of more severe brain injury have long been accepted as wide ranging and enduring for the injured person and those around them (Oddy et al. 1978[a]; Brooks et al. 1986).

Despite this growing consensus, our knowledge of the natural course of recovery and the impact of rehabilitation interventions remains inadequate. A number of factors contribute to the lack of information about rehabilitation outcomes in brain injury, not least of which is the relative newness of rehabilitation medicine as a specialty (Haffey and Lewis, 1989). The impetus for most early studies about recovery, was the desire to monitor and improve neurosurgical and neurological outcomes. To that end, death and survival have been the end states most often explored. Whilst such data is clearly useful for producing survival and mortality rates, it does not allow for the complexity of recovery occurring in the weeks, months and years after the immediate threat of death has passed.

The need to develop measures pertinent to the desired outcomes in rehabilitation, has led to an burgeoning number of tools available over the past decade (Wade, 1992). However, most research still focuses on early neurosurgical and neurological consequences, with long-term sequelae of brain injury predominantly defined in terms of neuropsychological deficit. Until this decade, there has been a dearth of research into the functional consequences of such impairments despite increasing awareness that for the individual and family, day to day functioning is of major concern (Brooks, 1991).

It is suggested that this lack of a co-ordinated approach to the measurement of such consequences and resulting absence of a shared language (Wade, 1992; Pentland and McPherson, 1994), is more than of purely academic concern. In many areas of provision, services are still based on a limited understanding of the problems people experience, and as such they may be ill-equipped to respond to difficulties which might even increase over subsequent years (Brooks et al. 1987; McKinlay and Hickox, 1988).

A further issue is that although most research on difficulties after brain injury has focused on those injured as a result of trauma, recent evidence suggests that similar problems may be experienced by individuals where injury is incurred through other causes including haemorrhage (Saveland et al. 1986; Ogden et al. 1990; Soryal et al. 1992).

The paucity of information is particularly apparent in the period following acute in-patient rehabilitation (Prigatano, 1988). The recent provision of comprehensive early in-patient rehabilitation for brain injured patients provides programmes aimed to alleviate some of the difficulties described above and prevent the avoidable consequences of such injuries. Despite these developments, follow-up services have traditionally been confined to medical review in an outpatient clinic and have tended to be uncoordinated and patchy (Brooks et al. 1986). It has also been suggested that the benefits of specialised rehabilitation may diminish after discharge from hospital (Garraway et al. 1980). And finally, the period shortly after discharge from hospital is one noted to be characterised by worry for both the patient and family (Bull, 1992).

As a consequence of the above, there is a need to explore further the nature of disability after brain injury and to evaluate interventions, in both the hospital and community setting, aimed at alleviating such consequences. This thesis reviews previous literature on the evaluation of disability in this population and has two main research goals.

Firstly:- a descriptive study is presented which aimed to describe functional status in patients after either traumatic and haemorrhagic brain injury, following discharge from in-patient rehabilitation to their own homes in the community. The specific hypotheses were that:

1. the subject's level of disability will be maintained or will have decreased at 6 weeks after discharge
2. the subject's level of disability will be maintained or will have decreased at 15 months after discharge

Secondly:- an intervention study was carried out to explore the role of home based visits as part of post discharge follow-up of patients after inpatient rehabilitation in order to address the findings of the first study. The specific hypotheses were that:

1. the level of disability in the intervention group will be maintained or decreased at 6 weeks post discharge
2. any improvement in function will be greater for the intervention group than for controls
3. satisfaction regarding information provided will be greater in the intervention than control group
4. the perceived health of the persons with brain injury and their carers will be unchanged or improved whereas that of the control group will be worse at 15 5months after injury
5. the service will be acceptable to patients and their families
6. the service will be acceptable to other professionals

A brief overview of the structure of the thesis is provided here to assist the reader.

## 1.2 Thesis Structure

Chapter 1 is an introduction to the subject area to be covered by this thesis and an outline of the remaining chapters now follows.

Chapter 2 provides a background of the epidemiology of the two types of brain injury examined in the study, traumatic brain injury and haemorrhagic brain injury. The scale of the problem is established and those groups at particular risk are highlighted.

Chapter 3 examines the meaning of outcome, with a particular focus on outcomes relevant to rehabilitation after brain injury. It concludes that there is a need for the assessment of outcome after brain injury to have a firm conceptual basis and that each area should be methodically explored.

Chapter 4 outlines the aims and methods of the first study. This comprised a prospective descriptive study of the functional level of those discharged from inpatient rehabilitation to their own homes the community. The nature of difficulties for people with traumatic brain injury are explored in relation to those who have experienced a haemorrhagic injury.

Chapter 5 presents the results of the first study - functional state in the community.

Chapter 6 outlines the aims and methods of the second study. This consisted of a prospective experimental design aimed to explore the effect of home visits to assist maintenance of functional state on discharge form inpatient rehabilitation to the person's home in the community.

Chapter 7 presents the results of the second study - the intervention study.

Chapter 8 discusses the results of the two studies in light of previous research and recent work published since commencement of the study. Finally, conclusions emerging from the findings will be made to encapsulate the contribution that this work provides to further understanding the consequences of brain injury.

CHAPTER 2.

# AETIOLOGY, EPIDEMIOLOGY AND MANAGEMENT OF BRAIN INJURY

## 2.1 Introduction

This chapter does not attempt to be an extensive review of the causes, population characteristics and pathophysiology of brain injury but rather aims to outline these issues to provide the context in which the research was done.

Any event which leads to alteration of the structural or biochemical environment of the brain, may result in damage. The consequences of such injuries are often wide ranging affecting both physical and psychological function and resulting in lasting or permanent disability and handicap. As traditional health services directed at either physical or mental health problems did not provide appropriate management for head injured patients, a number of specialist brain injury rehabilitation units have been established in recent years (Paton, 1996). There is a tendency for these units to cater predominately for those with more severe injuries who cannot be discharged home after initial treatment in the neurosurgical or trauma unit.

While many brain injury rehabilitation units were established to meet the needs of the head injured, they also commonly treat patients who have acquired brain damage as a result of other causes such as spontaneous intracranial haemorrhage and cerebral hypoxia, infections and metabolic insults. It is estimated that approximately 15% of strokes result from intracranial haemorrhage, either intracerebral or subarachnoid (Warlow, 1993).

Whereas stroke units provide rehabilitation for those with cerebral infarcts, they are often unable to meet the needs of those who have suffered intracranial haemorrhage where the sequelae are complex physical and psychological problems similar to traumatic brain injury (Soryal et al. 1992). Traumatic brain injury (TBI) accounts for 60%, and haemorrhagic brain injury (HBI) for 30% of patients treated at the brain injury rehabilitation unit, Edinburgh (Pentland, 1997).

## 2.2 Traumatic Brain Injury

### 2.2.1 Causes of Traumatic Brain Injury

Traumatic brain injury can be defined as damage to the cerebral hemispheres, brainstem and/or cerebellum as a result of the impact of an external force. The consistency of brain tissue has been described as similar to firm porridge within the rigid casing of the skull or as 'highly compressible but easily deformed' (Jennett and Galbraith, 1983). Such descriptions highlight that although the brain is well protected by the skull and meninges, it is vulnerable to distortion by externally applied forces. It

is usual to distinguish between open (or penetrating) injuries when a missile, sharp foreign object or a fragment of bone pierces the meninges and closed injury where the meninges remain intact

Reliable figures on the frequency of different causes of injury are not available as data tend to be based on hospital admissions and reported studies use different classifications of injury. There are also differences in the causes of injury between different countries and indeed within nations. Clearly this may be in part due to the activities people engage in, as well as the culture in which they live. Thus, for instance, a higher proportion of people are injured as a result of violence in urban, rather than rural areas. Age is also an important variable, with falls being more common in the very young and the elderly.

The 1985 UK figures suggest that the most frequent cause of injuries is falls (39%), with motor vehicle accidents (MVA) causing 24% and assaults 20% (Brookes et al. 1990) A more recent study of causation from in six areas in the USA (Harrison-Felix et al. 1996) found the majority of injuries to be caused by MVA at 53% (range 43%-63%), 19% (range 9%-30%) due to assaults and 19% (range 10-27%) due to falls. Further, when only severe injuries are considered, MVA is the most common cause of injury in the majority of countries (Jennett, 1996).

### 2.2.2 Mechanism of Injury

It has been established that there are two causes of injury to the brain: damage resulting from the impact (the primary insult) and the cumulative effect of systemic and intracranial complications of injury (secondary insults) (Graham and McIntosh, 1996). Primary brain damage can be classified as two broad types: focal and diffuse axonal injury.

#### 2.2.2(i) Focal Injury

Focal damage describes contusions or lacerations localised to a specific area(s) of the brain. This includes contusions at the site of impact and, in some instances, at the opposite side of the brain from where the impact occurred (contra coup injury). Acceleration-deceleration forces, which commonly occur in cases of MVA, can lead to focal damage to the poles of the brain. Thus the movement of the brain within the skull may result in the frontal and temporal poles impacting against the anterior and middle cranial fossa and, less commonly, the occipital pole against the posterior fossa (Miller et al. 1990).

The localised contusion and laceration can lead to secondary oedema or bleeding from larger vessels resulting in intracerebral, subdural or extradural haematoma.

#### 2.2.2(ii) Diffuse Axonal Injury

Diffuse axonal injury occurs when shearing mechanical forces affect the axons of nerves within their myelin sheath. It represents a further consequence of acceleration-deceleration forces and the rapid movement of the brain within the skull. Such disruption of the axons may occur outwith any other signs of contusion or haemorrhage within the brain. However, most focal injuries are accompanied by some diffuse damage (Teasdale and Mendelow, 1984) and it has been shown in animal studies that

the more extensive the diffuse injury, the worse the outcome both in the acute stages of care and in the long-term (Gennarelli et al. 1982). Although recent animal studies highlight potential advances in treatment of axonal injury (Povlishock and Christman, 1995), these have not as yet resulted in major changes in acute neurosurgical care.

### 2.2.2(iii) Secondary Insult

Secondary insults include both the biochemical and haemodynamic accompaniments of the primary insult and those resulting from concomitant injuries elsewhere in the body. Brain swelling, oedema and intracranial haemorrhage may be associated with increased intracranial pressure and compromise to the circulation of parts of the brain with resultant ischaemia and hypoxia. Systemic injuries such as compression of the chest in crush fractures or shock from excessive blood loss extracranially can interfere with the supply of oxygen and energy upon which the brain is so dependent. Much of modern acute management of trauma is directed at minimising these secondary insults.

## 2.2.3 Severity of Injury

Injury to the brain can range from relatively minor with transient effects, through to an insult causing threat to life. Given that one of the brain's primary functions is to maintain equilibrium of consciousness, the extent of disturbance to this equilibrium has long been accepted as an indication of this severity of injury. The initial severity of injury has been shown to impact on the chance of survival and also on the extent of recovery (Levin, 1995).

Description of the level of consciousness has been part of clinical management for many years (English, 1904) and it is now accepted practice to use standardised measures to describe and monitor the severity of the initial injury.

### 2.2.3(i) Depth of Coma

The most widely adopted measure of conscious state is the Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974; Teasdale and Jennett, 1976). It was developed in response to the inadequacy of subjective descriptions of coma, delirium and stupor to describe levels of impaired consciousness and the inadequacy and unreliability of using only the length of coma as an indicator of severity in head injury. It is based on the assessment of a person's capacity to function in three domains; verbal response, motor response and eye opening response. A score is given in each domain, providing a range in total score from 3 to 15, the lower score indicating a deeper state of impaired consciousness (Table 2.2-1). Although it was devised specifically for use in head injury, it has since been incorporated in the assessment of impaired consciousness in other conditions such as haemorrhagic brain injury.

*Table 2.2-1: Glasgow Coma Scale*

| Item Response | Score | Details |
|---|---|---|
| **Eye Opening** | | |
| None | 1 | Even to pain (supra-orbital pressure) |
| To Pain | 2 | Pain from sternum/limb/supra orbital ridge |
| To Speech | 3 | Non-specific response, not necessarily aware |
| Spontaneous | 4 | |
| **Motor Response** | | |
| None | 1 | To any pain; limbs remain flaccid |
| Extension | 2 | 'Decerebrate'; shoulder adducted and internally rotated, forearm pronated |
| Abnormal flexion | 3 | 'Decorticate'; shoulder flexes and adducts |
| Withdrawal | 4 | Arm withdraws from pain, shoulder abducts |
| Localises pain | 5 | Arm attempts to remove from supraorbital/chest pain |
| Obeys commands | 6 | Follows simple commands |
| **Verbal Response** | | |
| None | 1 | As stated |
| Incomprehensible | 2 | Moans/groans; no words |
| Inappropriate | 3 | Intelligible, no sustained sentences |
| Confused | 4 | Responds with conversation, but confused |
| Oriented | 5 | Aware of time, place, person |

The GCS score may be grouped to provide severity categories to provide a guide for emergency treatment and resuscitative measures (Table 2.2-2) (Teasdale and Jennett, 1974, Rimel et al. 1982).

*Table 2.2-2: Severity as measured by GCS*

| Glasgow Coma Score (GCS) | Severity of Injury |
|---|---|
| 13 or higher | Mild |
| 9-12 | Moderate |
| 8 or less | Severe |

The usefulness of the GCS to indicate severity of injury has been well established. It is particularly of benefit in predicting outcome in terms of death and survival in the initial post-injury phase. Further, those with moderate to severe injury on GCS are more likely than those with mild injury to be unemployed, have problems in activities of daily living and experience more neuropsychological difficulties (Jane and Rimel, 1982; Marshall et al. 1983). There is some debate as to which GCS is the most appropriate to record in order to predict outcome. Some studies have used both the initial GCS at the scene of the accident, and the worst in 24 hours (Zafonte et al. 1996). However, the consensus appears to be that the most reliable GCS is that taken after emergency resuscitation and this is increasingly used in order to document severity of injury (Marshall et al. 1983; Bishara et al. 1992; Ruff et al. 1993).

It has been shown that whilst a GCS may indicate an injury of only mild severity (13-15), the consequences of the injury are more in keeping with a moderate or severe injury (Williams et al. 1990). There is increasing evidence that those with a mild injury indeed experience more subjective complaints, such as headaches and sleep disturbance, than those with more severe injuries. For these reasons, other indicators including the length of post traumatic amnesia, are argued to be useful in more fully describing the severity of injury once the immediate threat of death has passed (Wade, 1992).

### 2.2.3(ii) Post Traumatic Amnesia (PTA)

Emerging from coma is a gradual process. There is commonly a period of time when the injured person no longer appears unconscious, but remains confused and unable to exhibit continuous memory. The time from injury until continuous return of day-to-day memory is known as the period of post traumatic amnesia and its duration has been shown to be a further indicator of the severity of injury (Forrester et al. 1994).

Early measures of PTA were based on when the patient would say they 'woke up' from their coma (Russell, 1932). Definitions were later modified to include the notion of 'continuous memory'(Symonds, 1940) and this has been accepted as a suitable definition with bands of PTA duration found to be indicators of severity of injury as shown in Table 2.2-3 (Teasdale and Jennett, 1974).

*Table 2.2-3: Severity on PTA*

| Duration of Post Traumatic Amnesia | Severity of Injury |
|---|---|
| Less than 5 minutes | Very mild |
| 5 to 60 minutes | Mild |
| 1 to 24 hours | Moderate |
| 1 to 7 days | Severe |
| 1 to 4 weeks | Very severe |
| More than 4 weeks | Extremely severe |

There are practical difficulties in reliably ascertaining the length of PTA retrospectively. People may have periods of lucidity, or 'islands' of intact memory and thus PTA may be underestimated (Gronwall and Wrightson, 1980). In addition, 'day-to-day memory' of early events may in fact be confabulation or, recall of what they've been told rather than what they've remembered. Further, there are frequent examples in the literature where researchers refer to PTA duration without specifying the way it has been assessed or the time after injury when the assessment of PTA has been made.

As a result of these difficulties, there is increasing evidence that mapping amnesia and orientation on a daily basis, using standardised tests, is necessary to achieve an accurate estimate of PTA. Measures advocated for use include the Galveston Orientation and Amnesia Test (GOAT) (Marshall et al. 1983) which provides a score out of 100 on questions regarding orientation to place time and person as well as memory (a test score of 75 or less is taken to be indicative of continuing post-traumatic amnesia). However, many existing measures, such as the GOAT are criticised on the grounds of being difficult to score and time consuming to use on a daily basis. A further criticism is that they are limited in focus. As a consequence, there is an increasing emphasis on developing better measures of PTA (Forrester et al. 1994). Matters are further complicated by the fact that if acute management has involved the use of sedative medication, the determination of PTA may be an inaccurate reflection of injury severity.

Given these caveats, to date there has been a continued reliance on retrospective measurement of PTA duration in the clinical setting as a useful measure for pragmatic reasons (Bond, 1990). In the absence of other reliable predictors, it is included in this study as an indicator of the severity of injury

### 2.2.4 Incidence of Traumatic Brain Injury

Establishing accurate information about the incidence of trauma to the brain is not a straightforward matter. A number of problems exist in the accuracy and generalisability of the data available with world-wide incidence of injury figures ranging from 150 to 400 per 100,000 of the population per year. As well as cultural and geographic differences, there are variations in methods of classifying injury, data collection and population sampling techniques. Despite improvements in documentation by the use of classification systems such as the International Classification of Diseases (ICD) codes, it is suggested by some that such incidence figures are over-estimates due to inadequate application of criteria (Jennett, 1996).

Whilst recognising these issues, it seems reasonable to accept the estimate of 250 per 100,000 per year experiencing traumatic brain injury of a severity requiring hospital admission in countries such as Scotland, England, USA and Australia and New Zealand. Based on these figures and the census of 1991 (General Register Office,1991; Office of Population,1993), approximately 139,820 people receive injuries necessitating admission to hospital each year in the UK, 12,756 of these in Scotland[1].

These data exclude many of those with mild injuries who either do not present at hospital in the first place, or for whom clinical decision is that admission is not warranted. One estimate is that as many as 85% mild injuries are treated without admission to hospital (Fife, 1987).

Most studies, irrespective of the country of origin, report brain injury rates as far more frequent for males than for females, with ratios of between 2:1 and 3:1.

There is a bimodal distribution of age related incidence of traumatic brain injury with the highest peak in males aged 20 to 30 years, and a second, albeit smaller peak in those over 70 years. The incidence of deaths has been declining since the late 1960's and is most recently estimated to be seven per 100,000 in the UK (Jennett, 1996) with increased mortality for older people.

### 2.2.5 Prevalence of Traumatic Brain Injury

Prevalence figures (those in the population with ongoing attributes of the disease or injury) were estimated to be 100 per 100,000 in Scotland in 1981(Bryden, 1989). Prevalence is estimated to be lower in recent studies at 62.3 per 100,000 (Moscato et al. 1994). Clearly such estimates rely on the adequacy of the definitions and measures used to describe deficits or attributes of the injury (Martin et al. 1988). Based on such estimates, between 35,000 and 56,000 individuals and their families in the UK might be expected to be living with the effects of head injury; 3,000 to 5,000 of them in Scotland.

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[1] Although the population of Britain has varied in the period since the 1991 census, the most recent estimates suggest these figures to be reasonably accurate as of June30th 1996, and furthermore, that the population of Scotland will remain at over five million for the next thirty years. Data supplied by General Register Office for Scotland.

## 2.3 Haemorrhagic Brain Injury

### 2.3.1 Causes of Haemorrhagic Brain Injury

For the purpose of this thesis, haemorrhagic brain injury (HBI) refers to non-traumatic intracranial haemorrhage in the form of subarachnoid or intracerebral haemorrhage, confirmed by CT or MRI scan. These are the criteria applied for designation as HBI in the brain injury rehabilitation unit in Edinburgh.

Spontaneous subarachnoid haemorrhage (SAH) is usually the result of rupture of a cerebral aneurysm or an arteriovenous malformation (AVM) which, with hypertensive vascular disease, also account for most cases of primary intracerebral haemorrhage (Warlow, 1993). Much less common causes include bleeding diatheses, anticoagulants, inflammatory diseases of blood vessels and tumours. Recognised risk factors for bleeding from vascular abnormalities include age, hypertension, smoking, alcohol and poor nutrition (Clinchot et al. 1994).

#### 2.3.1(i) Aneurysms

An aneurysm is a circumscribed dilatation of an artery and most intracranial aneurysms are saccular in type, occurring at vessel bifurcations. They range in size from a few millimetres to several centimetres (so called giant aneurysms). Until recently, most aneurysms were thought to result from a developmental weakness in the blood vessel wall, hence their description as congenital. However, now they are thought more commonly to originate from the damage caused by atheromatous deposits (Bannister, 1997) . With the pressure of blood flow over time, this area dilates disproportionately to the rest of the vessel, leading to stretching and ballooning. This area is therefore weaker than the rest of the vessel and may rupture causing bleeding in the surrounding area.

Aneurysms are most common in the anterior cerebral artery (35-40%), the carotid artery (30%) and the middle cerebral artery (20-25%) although they may occur in any blood vessel. In addition to the possibility of rupturing, expansion of an aneurysm may compress brain structures in the surrounding area. Thus some patients may present with symptoms of this local pressure effect on adjacent structures even in the absence of haemorrhage. Of those patients presenting to neurosurgeons, about 90% do so because of haemorrhage, 7% with local compression and the remainder are found incidentally (Lindsay et al. 1997). Rupture seldom occurs until the aneurysm is over 6mm in diameter but, paradoxically, giant aneurysm (>25 mm) are less likely to rupture probably because of thrombus reinforcing the inner wall (Whittle et al. 1982). Thus, rather than classifying aneurysms according to size, they are classified according to the neurological status of the patient at presentation. This will be discussed further in Section 2.3.3.

#### 2.3.1(ii) Arterio-Venous Malformation (AVM)

An AVM is a developmental abnormality of the intracranial veins and arteries. Enlarged arteries feed into a tangle of vessels or fistula, with oxygenated blood flowing directly into veins without passing through smaller arterioles and supplying brain tissue. The consequence is of a space occupying lesion of aneurysmal and dilated vessels which deplete oxygenation of brain tissue by shunting blood away

from normal tissue. This mass of vessels is classified according to a system which addresses the following features: size, pattern of venous drainage and location in the brain (Spetzler and Martin, 1986).

Despite this rather catastrophic sounding process, bleeding occurs less frequently, and mortality from such lesions is lower than from aneurysm rupture. Fifty percent of AVM's will bleed at some point and the most frequent age of patients presenting with an AVM is at aged 40 to 50 years (Bannister, 1997).

## 2.3.2 Types of Haemorrhage

Haemorrhage into the cranial cavity is defined as being intracerebral or extracerebral dependent on whether bleeding is into the brain tissue or its linings.

### 2.3.2(i) Subarachnoid Haemorrhage (SAH)

The subarachnoid space is the area between two of the protective layers covering the brain, the pia and the arachnoid. The intracranial blood supply is carried by vessels that run through the subarachnoid space with smaller branches cutting through the pia into the cerebral cortex. If there is bleeding into this space, it is known as a subarachnoid haemorrhage (SAH). Table 2.3.-1, illustrates the most frequent cause of SAH to be a ruptured aneurysm.

### 2.3.2(ii) Intracerebral Haemorrhage (ICH)

Rupture of blood vessels leading to bleeding into the brain substance are defined as intracerebral haematomas. There may also be associated bleeding in the subarachnoid space if rupture of the vessel approximates the cortical surface. Hypertension is reported as the main cause in the majority of cases although the actual proportion varies widely.

*Table 2.3-1: Cause and type of HBI (range of figures)*

| | Subarachnoid Haemorrhage | Intracerebral Haemorrhage |
|---|---|---|
| **Aneurysm or AV Malformation** | 50-60%<br>5-10% | 30% |
| **Hypertension** | - | 70-80% |
| **Other known causes (e.g. coagulation disorders, tumour)** | 5-10% | 10-15% |
| **Idiopathic** | 20-25% | |

Source: (Jennett and Galbraith, 1983; Lindsay et al. 1986; Selman and Ratcheson 1996[ab])

## 2.3.3 Severity of Haemorrhagic Brain Injury

The clinical condition of patients with intracranial haemorrhage is classified according to a system based on the GCS. One classification system was published by Hunt and Hess (1968) but this was

further developed by the World Federation of Neurosurgical Societies (WFNS) with a final version and recommendations published in 1988 (Drake et al. 1988). The two factors that were most closely associated with outcome were level of consciousness (as reported by the GCS) and the presence or absence of focal deficit as shown in Table 2.3-2.

*Table 2.3-2: WFNS Scale*

| Grade | GCS | Focal Deficit |
|---|---|---|
| **I** | 15 | Absent |
| **II** | 13-14 | Absent |
| **III** | 13-14 | Present |
| **IV** | 7-12 | Absent or Present |
| **V** | 3-6 | Absent or Present |

### 2.3.4 Incidence of SAH

Subarachnoid haemorrhage is estimated to occur in between 8 to 15 per 100,000 of the population per year and the mean age of rupture is around 50 years of age in most series (Mendelow, 1992; Selman and Ratcheson, 1996[a]). Without surgical intervention, there is a high level of mortality and morbidity associated with SAH. Thirty percent of patients who survive the original bleed, rebleed within 28 days and this incurs a death rate of 70%. Although the chance of rebleeding subsides, it is always higher than the rate for the general population at around 3.2% per annum. With or without surgery, there is a risk of developing complications such as cerebral ischaemia and vasospasm (25% incidence with 50% mortality) (Lindsay, 1992).

As a result of the risks of conservative management, surgical intervention has become the treatment of choice. Surgery consists of either directly clipping the aneurysm or performing coil embolisation of the vessel, and it was initially thought that postponing surgery for a week to 10 days after presentation was the optimum timeframe. However, there continues to be debate about when is the best time for surgical intervention (Chicoine and Dacey, 1997; LeRoux and Winn, 1997). The International Cooperative Study on the Timing of Aneurysmal Surgery (Kassel et al. 1990), demonstrated that there was no difference in outcome according to the timing of surgery for those individuals with poorer grades on initial presentation. However, for those who were alert on admission, outcome following early surgery (within three days) was better than when it was delayed to after 14 days. A separate analysis of the data for those patients admitted to North American centres found that for all patients, regardless of grade, early surgery resulted in improved outcome (Haley et al, 1992). The consensus from these studies is that early diagnosis and referral for neurosurgical assessment is essential in the management these patients.

### 2.3.5 Prevalence of SAH

It is difficult to estimate the numbers of people surviving SAH but living with deficit. Although people have been followed up in neurosurgical studies, commonly, the only measurement of outcome

has been fairly crude (survival/death). Until very recently, even neuropsychological outcome was merely assumed to be good although it has been shown that with more thorough assessment neuropsychological deficit can be determined. Bornstein (1987) found that 73% of those patients whom the neurologist had assessed as having a 'good' outcome had a degree of neuropsychological deficit. Others have reported persisting emotional and psychosocial difficulties in patients rated as having good neurological recovery (Ogden et al. 1990). Also, patients with poorer outcome are often excluded from follow-up studies as merely being exceptions to the 'good outcome' rule (McKenna et al. 1989[a]). There is, therefore, a lack of data on the longer term outcome of survivors of subarachnoid haemorrhage.

### 2.3.6 Incidence of Intracerebral Haemorrhage

Spontaneous intracerebral haemorrhage is more common than SAH reportedly occurring in between 12 to 20 per 100,000 per year (Mendelow, 1992; Selman and Ratcheson, 1996[b]). Mortality from a non-traumatic ICH is 50-60% and debates about the most appropriate acute treatment continue due to the lack of randomised controlled studies. The majority of studies have emerged from Japan and the consensus appears that surgical treatment remains controversial (Mendelow, 1992). Some individual patients may require surgery due to the increased pressure that a large haematoma puts the brain under and in this case surgical evacuation of the haematoma may be life saving. The second indication for surgical intervention is the cause of the haemorrhage. If there is a risk of rebleeding from an aneurysm or AVM, then surgical intervention may be carried out.

### 2.3.7 Prevalence of ICH

As with SAH, the prevalence of persistent deficit for these haemorrhagic events is not established. However, prognosis is worse for haematomas in the thalamus or basal ganglia and for those patients who have been in coma.

## 2.4 Early treatment and management of brain injury

It is clearly beyond the scope of this thesis to detail the acute management of brain injury. However, it is useful to briefly summarise the rationale behind treatment strategies. While there are clear differences between approaches to the management of traumatic cases from those due to non-traumatic haemorrhage, the overall principles are similar, as both tend to present as neurosurgical emergencies.

For most people who experience a traumatic brain injury, early treatment consists of careful initial examination followed by close observation to ensure that any deterioration is promptly acted upon. Indications of deterioration are alteration to conscious level and other vital functions such as blood pressure, respirations and pulse rate. In trauma, it is also necessary to assess for coexisting injuries, as about one third of all people with a head injury incur another injury (Jennett and Galbraith, 1983).

Where the patient presents with a severe injury, other investigations may be required to determine the nature of any intracranial haemorrhage or brain swelling. For those where such indicators reveal more

severe injuries, interventions to maintain homeostasis are required. As with other medical emergencies, this involves maintenance of a clear airway, ensuring adequate oxygenation and sustaining blood pressure within normal limits. In some cases, surgical intervention is required to evacuate haematomas, insert intracranial pressure monitors or minimise the risk of infection by, for instance, debriding wounds in cases of depressed fracture.

The skills of the trauma and neurosurgical teams are directed at preventing avoidable death and disability rather than in effecting repair to the damaged brain. Thus most of their effort is in preventing or controlling secondary insults described earlier. In addition, other specialists may be required to deal with extracranial injuries such as orthopaedic, peripheral nerve, chest and abdominal trauma. Highly skilled nursing and medical input is also required at this stage to prevent decubitous ulcers, renal dysfunction, chest infection, thromboembolism and joint contractures. Finally, early treatment should address the cognitive, emotional and behavioural consequences of injury which may be evident at this stage.

Once their medical condition has stabilised, a proportion of patients will have persisting impairments and disabilities which are best addressed by a multiprofessional rehabilitation team.

## 2.5 Rehabilitation Management

As early as 1972, it was recognised that the multiplicity of problems for the person with a brain injury required specific provision once the acute health crisis was dealt with as this sort of approach only deals with a certain number of the sequelae of brain injury (Scottish Home and Health Department, 1972). Such recommendations have been addressed by the establishment of specialist rehabilitation units throughout the world (Pentland, 1986; Pentland and Barnes, 1988; Pentland and Miller, 1988).

Rehabilitation is a relatively new term and even newer speciality within medicine. It is sometimes argued that the concept of rehabilitation is based on a restrictive model of health and medicine, focussing too much on the individual and too little on society (French and Swain, 1997; McLellan, 1997). However, even the earliest definitions were clear that rehabilitation should be concerned with the individual and their place in society. Jefferson in 1941 suggested that rehabilitation should be:

> 'the planned attempt under skilled direction by the use of all available measures to restore or improve the health, usefulness and happiness of those who have suffered injury or are recovering from disease. Its further object is to return them to the service of the community in the shortest time' (Jefferson, 1941).

This statement captures a number of ideas which are integral to the aims and the process of rehabilitation as it has developed. Jefferson clearly suggests that rehabilitation must have a holistic view of the outcomes that are relevant, and that the process is complex requiring a range of measures.

Such ideas have been further explored by a range of bodies including the Scottish Home and Health Department (1972), who identified the aim or outcome of rehabilitation as being to restore people 'to their fullest physical, mental and social capability'.

Further, the United Nations (1982) stated that rehabilitation is:

> 'a goal-directed and time-limited process aimed at enabling an impaired person to reach optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his life'.

Each of these definitions makes clear that rehabilitation needs to be focussed on the needs of the individual in a broad context. Thus it would seem that rehabilitation, as it has been defined, is not reductionist although the practice of rehabilitation may be.

The World Health Organisation (WHO) (1980) picks up on Jefferson's point concerning the variety of measures that might be required in the rehabilitation process by stating that:

> 'Rehabilitation is a problem-solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of disease, always within the limitations imposed both by available resources and the underlying disease'.

It is clear that the process of rehabilitation was not intended to be limited to intervening at the level pathology or disease process, but also to include restoration of function in both the individual sense (disability) and the societal (handicap). It is also clear that rehabilitation must recognise the extrapersonal 'limitations' which effect the level of disability or handicap, and increasingly it is identified as having a role in exerting influence on them. Thus, rehabilitation after brain injury must relate to a range of outcomes and this is further discussed in Chapter 3.

## 2.6 Concluding Comment

This chapter has introduced important concepts in brain injury. This sets the scene to examine in more detail the consequences that may persist beyond the scope of acute treatment. Chapter 3 examines such consequences and evaluates the outcomes that are of concern in the rehabilitation management of brain injury and thus this study.

CHAPTER 3

# REHABILITATION OUTCOMES IN BRAIN INJURY

## 3.1 What is Outcome?

The work of Alvedis Donabedian (1966) has been a major influence on modern developments in the field of measuring outcome. Donabedian suggested a conceptual framework for evaluating health care which explicitly defines three components: structure, process and outcome. Structure includes the facilities, equipment, staffing and other organisational aspects of care. Process refers to the services rendered to a patient during an episode of care whilst outcome is identified as the consequences of a health care episode. However, this definition only takes us part way to an understanding of what outcome is. Diller and Ben-Yishay (1987) rather poetically describe outcomes in rehabilitation as:

> ' . . . in a sense like paintings. They depict aspects of reality that can be portrayed in many ways, viewed from different perspectives, and understood from several frames of reference.'

The next section will discuss how to adequately define these 'aspects of reality' with specific reference to brain injury,

## 3.2 Outcome following Brain Injury

Evidence of an interest in examining the consequences of illness, injury and subsequent treatments can be found in the literature of most past civilisations long before the development of Donabedian's framework. Most early attempts to investigate such consequences were based on investigating simply whether the endpoint of death or survival was reached. This focus is unsurprising given that high mortality rates for many conditions have prevailed until relatively recently.

Even now, the initial outcome of interest after someone has had a brain injury, is whether or not they will survive. However, improved anaesthetic and surgical care has led to more people surviving the initial insult (Miller et al. 1992). As a result, there has been a shift from simply being satisfied with 'survival' as the desired outcome, to a need to ensure the optimum level of recovery for the individual as the desired outcome.

However, outlining precisely what constitutes recovery in the field of brain injury, is no easy task. The semantic difficulties of the word bedevil those who experience a brain injury and their families, as well as those who work within the field. The lay understanding of the term 'recovery', implies an all or nothing eventuality of 'returning to normal'. Alternatively, 'recovery' in neurosurgical usage, is the point at which cellular stability is restored. However, the outcome of complete cellular recovery is variable and may present as anything from a state of persistent coma through to what the family sees as a 'return to normal'. This difference in understandings of 'recovery' leads to problems for families

(Lezak, 1996) as many continue to wait for 'recovery' whilst in reality, the outcome may be a number of possible end states on a series of continuums.

## 3.3 Why Measure Outcomes after Brain Injury

There is increasing recognition of the need to measure outcomes for clinical, academic and financial reasons (Wade, 1992; Fratalli, 1993; Pentland and McPherson, 1994). Further, establishing the relationship between injury severity, treatments (or process) and outcomes is important for understanding the nature of the condition, the effectiveness of treatment and the efficiency of programmes.

However, measurement of outcomes can only be valuable if there is shared understanding of the terminology and merely choosing words other than 'recovery' is clearly not the solution. It has been suggested that the absence of such a language has precluded development within brain injury management and research:

> 'The interchangeable use of descriptive words has at times resulted in such high levels of ambiguity and confusion that it has impeded progress in the field'. (Almli and Finger, 1988)

This is echoed more recently by Wade (1992) with specific reference to rehabilitation:

> 'Neurological rehabilitation has made little progress over the last few decades, and one reason may be the complete lack of agreed methods of measurement. Improved information is necessary for progress, and usually leads to progress. One way to improve information is to make systematic, detailed observations using well-tested measures.'

Clearly, there is little debate that measuring outcome is important. However, providers, purchasers and indeed users of health care, face decisions regarding what outcomes to measure, what measures are the most appropriate to use, and also when and how to apply them.

## 3.4 Global Evaluation of Outcome

Given the range of outcomes possible after brain injury, it is no longer sufficient to merely categorise outcome in terms of death versus survival. An advance on this binary type of classification are scales with an ordinal array of categories. Such global scales have the advantage of being simple and easy to construct and use (Feinstein, 1987).

The Glasgow Outcome Scale (GOS) was developed in an attempt to address the issue of morbidity as an outcome variable following injury (Jennett and Bond, 1975). It represented a major advance in assessing the overall outcome in this population and continues to be advocated as a primary outcome measure for severe TBI (Clifton et al. 1992). Table 3.4-1 summarises the categories of the GOS.

*Table 3.4-1: Glasgow Outcome Scale*

| | |
|---|---|
| 1 | Death |
| 2 | Persistent vegetative state |
| 3 | Severe disability (conscious but dependent on others for daily activities) |
| 4 | Moderate disability (independent in daily activities and capable of participating in sheltered workshops or supported employment) |
| 5 | Good recovery |

Despite its potential utility in large population studies, the principal limitation in its application in rehabilitation is its limited sensitivity which has been widely recognised (Jennett et al. 1981; Hall, 1992). The same difficulties arise with similar measures such as the Disability Rating Scale (Rappaport et al. 1982).

The notion of outcome after brain injury as a series of continuums (Lezak, 1996) is integral to understanding the impact of brain injury on the survivor and their friends or family. Global measures are clearly unidimensional and have been developed from pragmatic rather than conceptual grounds. There is a risk that the complexity of outcomes is liable to be over-simplified by global measures developed outwith a firm theoretical basis or framework.

## 3.5 A Framework For Evaluating Rehabilitation Outcomes

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) framework (World Health Organisation, 1980), was developed to assist a better understanding of the nature of consequences in disabling illness. It divides the consequences of injury or illness into three levels that can then be examined (Table 3.5-1). As such, the framework provides a more complex structure of outcomes for the survivor of brain injury than referring to outcome as a global concept.

*Table 3.5-1: Abbreviated ICIDH Classification*

| | |
|---|---|
| **Impairment** | Abnormality or loss of psychological, physiological or anatomical structure or function. |
| **Disability** | Any restriction or lack (resulting from impairment) of ability to perform an activity within the range considered normal for a human being. |
| **Handicap** | Disadvantage for a given individual, resulting from impairment or disability that limits or prevents fulfilment of a role that is normal (depending on age, sex, social and cultural factors). |

### 3.5.1 Impairment

Much of the initial management in caring for people after brain injury is directed appropriately at the level of pathology or impairment. Indicators of the severity of pathological damage or impairment

include measures such as the GCS, length of PTA and imaging studies including Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) scans.

Neurological deficits may indeed be persistent, and impairment is therefore a focus of assessment even years after injury. However, there appears to be a bias towards evaluating outcome only in terms of impairment even within the rehabilitation literature (Ponsford et al. 1995). One reason for this may well be that 'abnormality or loss of psychological, physiological or anatomical structure or function' remains a prime concern in acute medical intervention. As such, the assessment and measurement of impairment has a comparatively long history within health care (Dejong, 1987).

### 3.5.2 Disability

Disability is defined in the ICIDH as 'the extent to which a person is unable to perform an activity in a manner or at a rate which is considered normal for that population' (World Health Organisation, 1980). Wade (1992) suggests that although the final goal of rehabilitation is to reduce handicap:

> 'it is probably easiest and most effective to concentrate upon disability'.

Although the ICIDH report is clear that factors such as psychological disturbance may contribute to reduced functional ability, the assessment of disability has until recently, been dominated by measures that look almost exclusively at physical aspects of functional activities. Injury to the brain results in disabilities of both mental and physical function with psychological factors often the most important in the long term (Jennett and Bond, 1975; Jennett et al. 1981; Gray et al. 1994). Nevertheless, there remains a tendency to use measures of purely physical disability to characterise the head injured population and decide eligibility for rehabilitation services (Fratalli, 1993; Heinemann and Whiteneck, 1995).

In order to address such issues, a number of disability measures have been developed with a broader range of functions than those covered in the more traditional measures whilst attempting to keep a firm conceptual basis. However, there is to date, no generally agreed and acceptable measure of disability within brain injury rehabilitation (Pentland and McPherson, 1994; Ponsford et al. 1995; McPherson and Pentland, 1997[a]).

### 3.5.3 Handicap

Handicap is defined in the ICIDH as the disadvantage for any given individual, resulting from impairment or disability, that limits or prevents fulfilment of a role that is normal (depending on age, sex, social and cultural factors) (World Health Organisation, 1980). Thus, the level of handicap is defined by the social environment of the individual and how that interacts with the impairment or disability for that specific individual. The ICIDH identifies six areas of handicap: orientation, physical independence, mobility, occupation of time, social integration and economic self-sufficiency. This area of outcomes research is less well developed than that of impairment or disability and many difficulties remain in its measurement (Roy and Hunter, 1992).

## 3.6 Evaluation of the ICIDH model

The ICIDH model has led to development of a more fulsome discussion of the consequences of illness and injury both in terms of what it achieves and also in its limitations (Heinemann and Whiteneck, 1995; Johnston, 1995).

One of the goals behind the development of the ICIDH model was to explore the links between impairment, disability and handicap. Recently Johnston (1995) suggested that the original model implied a directly linear relationship between the dimensions and that her research found this was not the case.

The original text highlights a degree of linearity by presenting each dimension as graphically leading to the next as shown in Table 3.6-1.

*Table 3.6-1: Relationship between Impairment, Disability and Handicap*

| Impairment → Disability → Handicap |
|---|

There is no doubt that the representation of the model above is simplified. The relationship between dimensions is clearly complex in that alteration at a structural level may not lead to disability (i.e. functional consequences of an impairment do not necessarily arise). Further, extensive handicap may occur with apparently minimal disability. It is noteworthy that this issue of the complexity of the relationships is explicitly discussed in the original text (World Health Organisation, 1980)

A further point emerging from Johnston's argument, is that the suggested lack of a link between the three dimensions may in part be due to lack of satisfactory measures, rather than the limits of the framework itself. Heinemann and Whiteneck (1995), highlight that relatively few studies have explicitly explored the links between impairment, disability and handicap following brain injury. He suggests that it is, indeed, the lack of adequate measures which has led to an apparent lack of relationship between severity of injury and disability in past studies.

Another criticism of the ICIDH model is that it emerges from, and perpetuates, a solely medical view of disability (French and Swain, 1997). Oliver (1990) has argued that the model is individualistic and does not fit with the view of disabled people and that society alienates and estranges them far more than the disabilities themselves.

A recent reprint of the ICIDH model has acknowledged such criticisms and accepts that a revision of the ICIDH needs to:

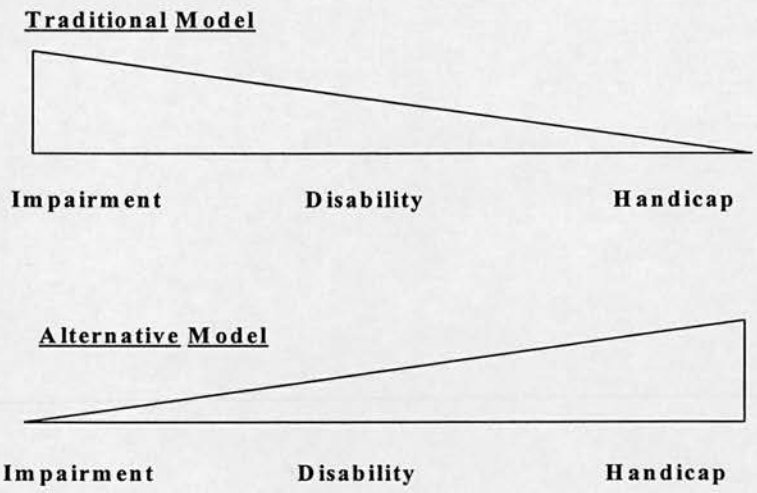
> ' clarify the role and interrelationships of environmental factors in the definition and development of the different aspects of the ICIDH, most notably - but not exclusively - handicap.' (World Health Organisation, 1993)

And further it was recognised that the revision should:

> 'improve the presentation and illustration of the way in which external factors affect the ICIDH components' (World Health Organisation, 1993)

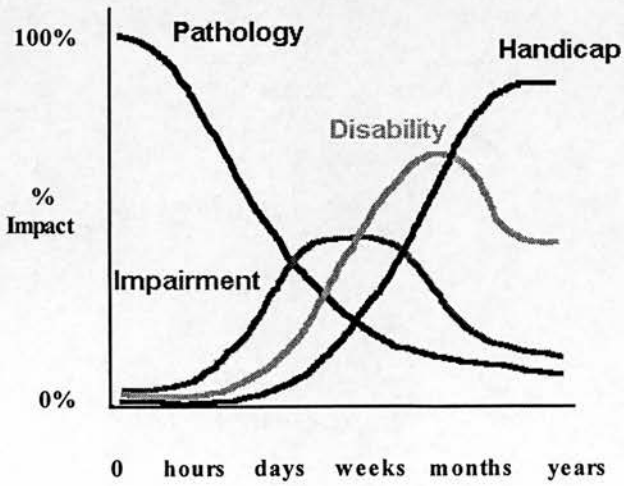
A number of alternative diagrammatic representations of the ICIDH model have been put forward in an attempt to explore the inadequacies highlighted in this section. Sloan (1996) has proposed a model that embodies the relative importance of each component of the ICIDH model as in Figure 3.6-1. Sloan suggests that impairments and disabilities not impinging on the individual's level of handicap do not require direct intervention and therefore, one must question whether they should they be assessed and measured at all.

*Figure 3.6-1: Traditional and Alternative ICIDH Models*




Wade suggests that time is the factor of importance (Wade, 1993). Thus, as shown in Figure 3.6-2, with the passage of time after the insult, pathology, impairment and disability are of less importance than disability and handicap and eventually, it is the social construct, handicap, which has most impact on the person's life. Thus in brain injury, post traumatic epilepsy may be well controlled by medication such that the incidence of seizures is reduced. However, the person's ability to continue in their work role, say as a lorry driver, will remain compromised.

*Figure 3.6-2: Relationship of time to ICIDH Model*



By providing a conceptual framework that can be tested and criticised, the ICIDH model has clearly advanced our knowledge and understanding of the consequences of illness or injury. Further, the criticisms do not seem to justify an assumption that functional loss, as described in the ICIDH is of little importance to people after brain injury. Rather, it appears more work is required to delineate those areas of function most important to patients.

## 3.7 Quality of Life and Health Status

In addition to the importance attached to measuring social disadvantage inherent in the concept of handicap, increasing attention is given to issues of quality of life (QoL), life satisfaction and health status or well- being. Indeed these terms are sometimes used as interchangeable with handicap or are considered to approximate it (Wade, 1992). However, reference to the ICIDH areas of handicap would suggest that neither quality of life nor health status are measures of handicap. One difficulty arises because the concept is intuitively familiar and therefore appears undeserving of close definition. The vagueness of the concept has been widely recognised (Fallowfield, 1990; Fallowfield, 1996) and some would doubt that it can be measured at all (Price and Harding, 1995).

Whiteneck (1994) argues that QoL is a composite of impairment, disability and handicap perceived from the person's point of view, ie perceived health status, activity limitation and role limitation. She feels that there is a dynamic element that is affected by the passage of time and accumulation of secondary impairments, disabilities and handicaps.

A further difficulty of measurement in the area of quality of life and life satisfaction is that there is still really no universally accepted method or approach to its measurement and many measures are psychometrically weak (McDowell and Newell, 1987). Gill and Feinstein (1994) have challenged the merit of existing QoL measurements in a recent article on the basis that although purporting to measure QoL, most do not in fact do so. They comment that:

> 'QoL is a uniquely personal perception, denoting the way that individual patients feel about their health status and/or non medical aspects of their lives, most measurements of QoL in the medical literature seemed to aim at the wrong target'.

It is likely that the long standing debate about the measurement of quality of life will continue for some time, but adequate definition of QoL is vital before consensus about how to measure it can be reached (Bergner, 1989; Fallowfield, 1996). In the mean time, it has been suggested that perhaps rather than trying to act directly to measure quality of life, measuring factors that seem to be indicative or to contribute to quality of life is suitable (Kind, 1988).

## 3.8 Satisfaction with services

The principal focus in both studies presented in this thesis was to describe outcome in terms of functional status in the period after in-patient rehabilitation, rather than to attempt to evaluate the effects of the treatment received in hospital. The second study does introduce an intervention in the

form of an outreach nurse and consequently an anonymous questionnaire directed at eliciting the views of patients and their carers is used.

There is an appropriate growing interest in including patient satisfaction or social acceptability measures in studies evaluating the quality of health care (Fitzpatrick, 1993). The National Health Service and Scottish Consumer Council (1995) has recommended seeking the view of the 'consumer' as an essential component in the improving health care delivery. Indeed, the Patient's Charter for Scotland includes a commitment to involving patients in decisions about their care, and assurance that their views on services will be sought.

However, there are a number of difficulties in the assessment of satisfaction. The use of questionnaires to address the patient's viewpoint has been widely criticised on the basis that it is most frequently the issues regarded as important by the professional that are considered rather than the priorities of the user (Attkinson and Greenfield, 1996). It is further suggested that criticisms of services are rarely sought or facilitated (Bell et al. 1993). In addition, the rush towards carrying out 'satisfaction surveys' has led to a predominantly poor standard in such measures even amongst those that have been developed as generic satisfaction indices (Williams, 1994). There is no doubt that the view of service users is an important outcome. However, it is also clear that one must exercise caution in the development of such measures and the interpretation of information emerging from them. As Whitfield and Baker state

> 'Poor questionnaires act as a form of censorship imposed on a patient. They give misleading results, limit the opportunity of patients to express their concerns about different aspects of care, and can encourage professionals to believe that patients are satisfied when they are in reality highly discontented' (Whitfield and Baker, 1992)

## 3.9 What should be measured?

In order to choose what should be measured, one needs to be clear about the purpose of the measurement. It was suggested in section 3.3, that there are a number of reasons for addressing outcome measurement in brain injury. Such factors include the need to increase our understanding about the condition itself, to evaluate the effectiveness of treatments and to measure the efficiency of programmes. In the case of evaluating interventions, Bergner (1989) suggests that one should measure those factors *likely to be* affected by the intervention, those which *might be* affected, and indeed factors that are *quite unlikely to be* affected. Such a comprehensive approach is not always feasible and Long (1985) advises ensuring those outcomes concerned with effectiveness are prioritised over those reflecting efficiency. Further, satisfaction with services must be measured if acceptability of service is considered an important variable.

Choosing those variables is not necessarily a straightforward process, but, the ICIDH model offers a structured framework by which a number of rehabilitation outcomes can be explored. Despite criticism, it has been advocated as a 'logical way of looking at outcomes' in the case of brain injury (Diller and Ben-Yishay, 1987).

Despite the complexity of the ICIDH model, the most well explored area after brain injury is impairment. A wealth of literature now exists describing the impairments that this group of people experience in terms of hemiparesis, dysphasia, cranial nerve palsy, epilepsy and ataxia (Jennett et al. 1981; Richardson, 1990). Many measures of cognition, although able to assess the nature and level of impairment, are criticised for being unrelated to the 'real life' functional performance (level of disability) of the individual (Sunderland et al. 1993; Newcombe and Artiola Fortuny L. 1979; Ponsford and Kinsella, 1991).

In terms of disability, our knowledge is meagre in comparison as global measures are still the most frequently used and, indeed continue to be advocated for use (Clifton et al. 1992). One of the principal reasons for measuring disability is to be able to better describe the functional consequences of brain injury in a wide range of activities (Jeffrey, 1993). However, measuring disability in isolation to the perceived impact of those disabilities on the broader social functioning of the individual is of limited value. It is therefore perhaps inevitable that one must consider employing a range of measures when attempting to gauge outcome after injury.

## 3.10 Important concepts in Measurement

It is sometimes implied that assessment and measurement mean the same thing. However, measurement is merely one aspect of assessment. The following definitions help to distinguish between the two (Wade, 1992). Measurement is 'the use of a standard to quantify an observation' whereas assessment is 'the process of determining the meaning of measurement'. It is clear that a measure must have certain properties if it is to quantify or to be a standard. Comprehensive discussion about the important psychometric properties of measures is contained elsewhere (Streiner and Norman, 1989) but it is worth mentioning them briefly within this text.

An instrument should have *validity* in that it measures what it sets out to measure. If it appears to do so, it is sometimes described as having *face validity*. If it can be ascertained that there is a firm conceptual basis linking the measure to the phenomenon it is theoretically measuring, it is said to have *construct validity*. Where it is possible to correlate a scale with some other recognised measure of the same phenomenon, preferably one accepted in the field as a 'gold standard', the scale is described as possessing *criterion validity*.

In addition to measuring what it purports to measure, an instrument should give the same result consistently when used repeatedly in a stable situation i.e. it should be *reliable*. Ideally used in the same circumstances with no change having occurred in the items being measured the same examiner should get the same results *(intrarater reliability)* and different examiners should also show high levels of agreement *(inter-rater reliability)*.

The truly ideal scale, which probably does not exist, should in addition to having the properties of validity and reliability, be sensitive to change over time, be comprehensive covering a broad range of relevant activities and finally should be easily used and widely applicable. There is a profusion of

scales which go nowhere near meeting this ideal. Indeed, many measures of disability are developed by single institutions, are never used anywhere else and are of dubious value even in the institutions using them (Pentland and McPherson, 1994).

## 3.11 Concluding Comment

This chapter has set out to explore the meaning of 'outcome' after brain injury. The argument has been made that the ICIDH has provided a useful framework of outcomes after brain injury. The following chapter describes measures of outcome used in the study of a brain injured population after inpatient rehabilitation.

CHAPTER 4

# FOLLOW UP INTO THE COMMUNITY - AIMS AND METHODS

## 4.1 Introduction - Background and rationale of study

In the previous chapter, the many effects of brain injury have been examined and a framework for assessing a range of outcomes has been evaluated. It has been argued that early rehabilitation aims to alleviate handicap, primarily by restoring function but also by preventing further impairment. To that end, each level of the ICIDH hierarchy warrants investigation as an outcome potentially affected by rehabilitation. As a result of the increased requirement to measure the wider aspects of recovery, evidence has been accruing which attests that rehabilitation after brain injury improves outcomes in terms of reducing disability (Cope, 1995). However, to date the predominant focus has been on impairment such that our knowledge of the nature of the disability and handicap lag behind.

All too frequently, outcomes after discharge from in-patient services remain unexplored and tend to be restricted to examining impairment or to be based on rather limited definitions of disability (Ponsford and Kinsella, 1991; Sloan and Ponsford, 1995). Also, those post hospital discharge studies which have been reported, frequently omit the early period after discharge from relatively long inpatient stays.

This is of interest and concern for a number of reasons. Firstly, it has been suggested that interventions to improve levels of functioning after brain injury are dependent on context. That is to say, generalisation of the abilities gained from the hospital to the person's home environment cannot be assumed to occur (Prigatano, 1988; Moore Sohlberg and Raskin, 1996). However, it has been common practice for follow up to be concentrated in an outpatient clinic i.e. in a hospital setting (Livingston, 1986; McMillan et al. 1988; Pentland and Miller, 1988; Barnes and Skeil, 1996). Secondly, there is a lack of evidence as to whether improvements in function made during rehabilitation are maintained in the long-term (Garraway et al. 1980; Cope, 1995; Hall and Cope, 1995; High et al. 1995). Thirdly, although the period of time soon after discharge has been identified as difficult for other patient populations and their families (White and Holloway, 1990; Bull, 1992) there is little information specifically regarding this time period for the brain injured population. These factors are all the more concerning given the reports that difficulties for the individual and their families persist and may get worse over time (Brooks et al. 1986; Lezak and O'Brien, 1988; Rappaport et al. 1989; Thomsen, 1992).

Questions therefore remain as to whether circumstances in the early weeks after discharge from successful in-patient rehabilitation might have important effects on the longer term outcomes for these people and their families. Certainly anecdotal reports (Hopkins, 1992; Seed, 1994) and some

retrospective work (Hubert, 1995) indicate that problems for people occur soon after discharge. Such findings suggest that prospective studies of this period are needed.

This chapter describes the hypotheses and methodology of a prospective study of the nature of disability and reported difficulties in a group of people who have received comprehensive in-patient rehabilitation following brain injury.

## 4.2 Aims and hypotheses

The primary focus of the study was to investigate the nature of disability in a population of people who had experienced a recent brain injury and had undergone inpatient rehabilitation.

To that end the main hypotheses were that

1. the subject's level of disability will be maintained or will have decreased at 6 weeks after discharge
2. the subject's level of disability will be maintained or will have decreased at 15 months after discharge

The corresponding null hypotheses were that

1. the subject's level of disability at 6 week follow up will not be significantly lower than at discharge
2. the subject's level of disability at 15 month follow up will not be significantly lower than at discharge or at 6 weeks

In addition to these hypotheses, a number of subsidiary aims were also considered in this study. In light of suggestions that the early period after inpatient care may be difficult, information regarding specific areas of concern for survivors and their families in the weeks following discharge were explored. As highlighted in the previous chapter, there are conflicting findings regarding the relationship between severity of injury and outcome. To that end the relationship between severity of insult, level of function, reported difficulties and carer distress at six weeks and fifteen months after discharge will be reported. As part of this, the relative strengths and weaknesses of the measures of outcome used will be discussed.

## 4.3 Methodology and procedure

This section describes the measures used in the study and addresses the rationale behind their inclusion. Discussion about the conceptual issues involved in assessment and measurement has been previously considered in Chapter 3.

### 4.3.1 Disability Measures

The major focus of this study was to investigate the nature of disability after brain injury. The measures chosen differ both in the range of items covered, and in the method of scoring employed.

An outline of each measure follows and Table 4.3-1 (on page 31) provides a summary of the component items of each scale and its scoring method.

### 4.3.1(i) The Barthel Index

The Barthel Index records the patient's level of dependence in ten activities of daily living (ADL) commonly disturbed in those with physical disabilities (Mahoney and Barthel, 1965). The original scoring was in five point increments from 0-100 but it is now the convention to rate each item from 0 (dependent) to 2 or 3 (independent) with total possible score ranging from 0 to 20, with higher scores indicating greater independence. It has been found to be a reliable scale (Collin et al. 1988; Roy et al. 1988) in terms of examining dependency in ADL and is widely used in rehabilitation practice.

### 4.3.1(ii) The Glasgow Outcome Scale (GOS)

The GOS has been comprehensively described in Chapter 3 and was included in this study as it is the most widely used measure of outcome in head injury studies (Clifton et al. 1992; Wade, 1992).

### 4.3.1(iii) The Office of Population, Censuses and Survey's (OPCS) Disability Scale

This measure was devised and validated for surveying the prevalence of disability in populations (Martin et al. 1988). Further, its utility, validity, reliability and sensitivity have been established within a clinical setting (McPherson et al. 1993; Wellwood et al. 1995; Hunter, 1996).

The conceptual basis of the OPCS scale is that of the ICIDH notion of disability and it covers all the principal areas of disability in the ICIDH. It asks what the person 'can do' as opposed to what they 'do do'. It assesses 13 functional areas and individual items are scored from 0 to a maximum of 12.5 according to the subject's ability to perform the function. The areas of function assessed, the weighting applied to items and the overall scoring were based on a series of surveys of opinion with that process described comprehensively in Martin et al's 1988 publication.

A score for each dimension is obtained by reference to the scoring manual. Rather than adding each of the thirteen items together to get a total score, Martin et al (1988) suggested that simplicity was aided, and sensitivity was not lost, by calculating an overall severity score using a formula from the worst three scores as follows:

*Formula for OPCS Overall Severity Score:*

$$(\text{worst score}) + (2^{nd}\ \text{worst score} \times 0.4) + (3\text{rd worst score} \times 0.3)$$

*In the case of a patient scoring 11.5 in two dimensions, 7.5 in another and 4.5 in two others the Overall Severity Score would be* $(\underline{11.5}) + (\underline{11.5} \times 0.4) + (\underline{7.5} \times 0.3) = \underline{18.3}$

In contrast to the Barthel Index, higher scores correspond to greater levels of disability or reduced independence.

### 4.3.1(iv) The Functional Independence Measure (FIM)

The FIM was devised by a national taskforce of clinical, research and administrative experts in rehabilitation in the United States of America as an instrument for general use in rehabilitation

practice (Granger et al. 1986). It was originally developed to measure 18 core areas of function at four levels of dependence, and as such, to be a 'minimum data set'. It has since been validated in a seven level score format (Chau et al. 1994; Hamilton et al. 1994) and is now widely used internationally (Hall et al. 1993). For each item, a score of 1 indicates complete dependence on others to achieve the activity, and a score of 7 represents complete independence. In contrast to the OPCS, it addresses what the person actually does rather than what they may be able to do.

### 4.3.1(v) The Functional Assessment Measure (FIM + FAM)

The Functional Assessment Measure (FAM), was developed as an expanded version of the FIM specifically for use with brain injured patients by the addition of 12 items (FAM) to the 18 items of the FIM (Hall, 1992; Pentland and McPherson, 1994). The additional 12 items, which constitute the FAM component, cover a greater range of cognitive and psycho-social functions. Thus, the complete FIM + FAM comprises 30 items with the same scoring format as the FIM. While validity and reliability data on the FIM is increasingly available in published literature, such information with respect to the FIM+FAM is scant. As part of this study, reliability and validity have both been examined (McPherson et al. 1996; McPherson and Pentland, 1997[a]; McPherson et al., 1997) and copies of the manuscripts are supplied as Appendix (i), (ii) and (iii).

One of these validity studies (McPherson et al, 1997), focused on the cognitive items of the FIM+FAM as these particular items had been based on relatively pragmatic, clinical principles (Hall, 1992). As there is no scale that might be considered a 'gold standard' measure of cognitive function, the study explored the relationship between impairment on neuropsychological tests, and items in the cognitive subscale of the FIM+FAM.

The study indicated that the FIM+FAM was sensitive to detecting functional consequences of cognitive deficit when compared with the neuropsychological tests. However, rather than specific deficits relating to specific functional consequences, impairment in any cognitive domain was associated with a broad range of functional consequences for the individual as reflected by the FIM+FAM. This study was carried out at a relatively early stage of recovery (median time between injury and assessment was 35 days, range 7-77days). It may be that the capacity of both FIM+FAM cognitive items, and neuropsychological measures to detect specific mental deficits, are likely to be overwhelmed by the generally widespread and severe nature of cognitive disturbance. A further explanation may be that the particular FIM+FAM dimensions lack specificity in their definition leading to a variety of interpretations and as a consequence leading to poorer inter-rater reliability.

In the inter-rater study (McPherson et al. 1996), the majority of items showed percentage agreement in excess of 80% between the two raters. However one item, 'Adjustment to Limits', was found to have a percentage agreement of less than 60%. Kappa results indicate a satisfactory inter-rater agreement for all but the same item, 'Adjustment to Limits' even when using a quite conservative value of an acceptable kappa at 0.4 (Landis and Koch, 1977; Fleiss, 1981). Higher kappa values occurred for items concerned with ADL or mobility as might be expected due to the accepted

conceptual difficulties of measuring psychosocial and cognitive function (Diller and Ben-Yishay, 1987; Ponsford and Kinsella, 1991; McPherson et al, 1997).

Confidence intervals on the raters' scores highlighted possible observer bias in four items and this was confirmed on a Wilcoxon test as follows: Employability $z=-2.52$ ($p=0.01$), Writing $z=-2.40$ ($p=0.02$), Comprehension $z=-2.02$ ($p=0.04$) and Problem Solving $z=-2.02$ ($p=0.04$). The FIM+FAM manual advises raters to award the lower of two scores if there is some doubt as to which level to assign. Discussion between the two raters at completion of the study, considered that one factor contributing to these differences, was that one rater applied this principle more rigorously. Given these findings it was decided that the measure was appropriate for inclusion in the present study.

The following table (4.3-1) highlights the principal features of the disability measures.

*Table 4.3-1: Summary of the Principal Features of Disability Measures*

| Measure | Items Assessed | Scoring Method |
|---|---|---|
| The Modified Barthel Index | feeding*, grooming*, bowels*, bladder*, dressing*, toilet use*, bathing*, *transfers*†, *walking*†, *stairs*† | Individual item scores (0-2 or 3). Total disability score (0-20) where the lower the score the greater the level of disability. |
| The Glasgow Outcome Score (GOS) | global outcome | One score (1-5) where 1 indicates death and 5 good outcome. Levels in between are intended to reflect different levels of disability. |
| The Office of Population Censuses and Surveys Scales of Disability (OPCS Scale) | *locomotion*†, reaching and stretching, dexterity, personal care*, continence*, seeing, hearing, communication, behaviour, intellectual functioning, consciousness, eating drinking and digestion, disfigurement | Individual item score (0-12.5). Total overall severity score (0-21.4) is calculated from the three worst item scores and may be grouped into ten severity levels. The higher the score the greater the level of disability. |
| The Functional Independence Measure (FIM) | feeding*, grooming*, bathing*, dress-upper*, dress-lower*, toileting*, bladder*, bowel*, *bed/chair transfers*†, *toilet transfers*† *& bath transfers*†, *walking/wheelchair*†, *stairs*†, comprehension, expression, social interaction, problem solving, memory | Individual item score (1-7) based on degree of assistance (help, supervision, aids required or safety concern). The lower the score the greater the level of disability. |
| The Functional Assessment Measure (FIM+FAM) | swallowing*, car transfers†, community mobility†, reading, writing, speech intelligibility, emotion, adjustment to limits, employment ability, orientation, attention, safety judgement (to be used in conjunction with the items in the FIM) | As for FIM |

* = Self-care items; † = *Mobility items*

### 4.3.2 Other Measures

Although the clear goal of this study was to explore the nature of disability after brain injury rehabilitation, it was decided to also consider other aspects of outcome. To that end, a number of other measures were included. This was done to ensure a comprehensive understanding of the functional limitations for the individual within the context of factors highlighted as important outcome variables as discussed in Chapter 3. In addition demographic data was collected from the medical records with confirmation of some information provided by the Head Injury Database at the Regional Neurosurgical Unit.

#### 4.3.2(i) Semi-structured interview

This included a semi-structured interview format to elicit broad areas of difficulty and to specifically enquire as to areas of information required by either the patient or their relative. As part of this interview, carers were asked 'are there any areas you would like more information on?' In this way, concerns were sought without prompting by the interviewer.

After spontaneous questions had been raised and discussed, the interviewer went through a list of potential subject areas to elicit further requests for information not yet mentioned. The interview format [Appendix (iv)]was based on unstructured interviews with a pilot group of 30 patients and their carers prior to the study.

#### 4.3.2(ii) Relative Questionnaire

As the semi structured interview was newly developed, it was augmented by using the Relative Questionnaire (RQ) (McKinlay and Hickox, 1988). This questionnaire has been used in a number of studies to detail the relative's view of problems occurring since the injury (Brooks and McKinlay, 1983; Brooks et al. 1986; Anderson et al. 1996). Despite its relatively widespread use, the reliability has only recently been tested and confirmed by researchers other than the authors (Hellawell and Signorini, 1997).

There are 50 items in eight categories - Physical and Sensory Problems, Subjective Symptoms, Emotional Disturbance, Disturbed Behaviour, Language, Memory, Dependency and Social Behaviour. Most items are scored according to whether there has been an adverse change since the injury. A typical item is shown below, with a copy of the questionnaire provided in Appendix (v).

*As a result of the head injury, does the injured person suffer problems with their eyesight?*

*No change (score=0)*
*Rather worse since injury (score=1)*
*Much worse since injury (score = 2)*

Thus a score of zero in a dimension indicates no change has been noted by the relative as a result of the injury.

#### 4.3.2(iii) Edinburgh Rehabilitation Status Scale (ERSS)

As discussed in Chapter 3, measurement of handicap has been less well developed than that of either impairment or disability and it was not the aim of this study to investigate handicap in detail.

However, it was decided that to include a measure approximating handicap would allow a fuller discussion of the issue of disability and its impact on both the individual and their family. The Edinburgh Rehabilitation Status Scale (Affleck et al. 1988) was chosen and is described in Table 4.3-2. The ERSS was used in preference to other scales purporting to measure handicap for a number of reasons. Firstly, reliability and validity data was available (Affleck et al. 1988; McPherson et al. 1992) and recent work has highlighted its use in populations with mixed disabilities (Fulton, 1992; Davey, 1994). Furthermore, assessment using the ERSS is based on the level of handicap as reported by the individual, the carer or relative, and also the assessor. Using this collective viewpoint in addition to the assessments focussing on the patient, and those exploring the relative's viewpoint was felt to be a major advantage over purely self report versions of handicap scales given the characteristics of the brain-injured population in which lack of insight is a commonly reported phenomenon.

*Table 4.3-2: Summary of the Principal Features of ERSS*

| Measure | Items Assessed | Scoring Method |
|---|---|---|
| The Edinburgh Rehabilitation Status Scale (ERSS) | This is defined by the authors as a measure of medico-social dysfunction. It therefore allows a broad perspective of the impact of disability in four areas: required support; level of activity; social isolation; and effect of impairment on lifestyle. As such it further describes the effects of functional limitation on the individuals life in the context of an operationalised form of handicap. | Individual item score (0-7). Total overall severity score (0-28) is calculated from adding each subscale score together and a percentage score may be calculated by multiplying the total by 3.71. The higher the score, the greater the level of medico-social dysfunction. |

### 4.3.2(iv) Perceived Health

In the previous chapter, the ICIDH was argued to be a useful framework for outcomes after brain injury. However, it was also suggested that outcomes not covered by the model, such as perceived health, may be of interest.

It had been intended to use the UK version of the Sickness Impact Profile (SIP) known as the Functional Limitations Profile (FLP) (Charlton et al. 1983). This measure in some ways crosses the boundary between impairment, disability, handicap and indeed perceived health. Despite these conceptual difficulties, an attempt to use it in the first phase of the study was made as it had been shown to be useful in the head injured population (Smith, 1992).

However, a number of problems precluded its continued use. The main difficulty for the study population was the number of questions asked (136 in total ). Given that the majority of the areas in the FLP were addressed within the other measures used, it was decided to abandon its use. Questions not addressed explicitly in the other measures but felt to be important were included in the interview. These consisted of questions about involvement in household chores, management of finances, and participation in leisure activities.

However, this left a gap in the study with regard to a measure allowing a solely subjective viewpoint to be measured. In order to redress this, a number of other measures discussed in Chapter 3 were

considered. One measure, the UK version of the Medical Outcomes Study (MOS) Short Form 36 (SF36 - Table 4.3-3) (Ware and Sherbourne, 1992), was selected to be part of the 15 month follow up for a number of reasons. The major advantage over the FLP was its relative brevity at 36 items. Another factor was that considerable reliability and validity data was available (Brazier and Jones, 1992; Katz et al. 1992; Ware, 1993). A further asset was that a number of studies had produced normative data (Brazier and Jones, 1992; Jenkinson et al. 1993). This meant there was potential to use it as an indicator of carer well-being as well as that of the brain injured individual. It was administered in a small pilot group of brain injured people (n=5) and found to be acceptable.

*Table 4.3-3: Summary of the Principal Features of SF36*

| Measure | Items Assessed | Scoring Method |
|---|---|---|
| Short Form 36 (SF36) | 36 items which are grouped into 8 dimensions. Physical Functioning (10 items), Social Functioning (2 items), Role Limitations due to Physical Problems (4 items), Role Limitations due to Emotional Problems (4 items), General Mental Health (5), Energy/Vitality (4), Bodily Pain (2) and General Health Perceptions (5) | Item scores are transformed to allow each dimension to be given a percentage score. |

### 4.3.2(v) Carergiver Strain Index

In a further attempt to ensure the relative's perspective on the difficulties was considered, a questionnaire called the Carergiver Strain Index (Robinson, 1983) was incorporated into the 15 month assessment. Although this was designed for use in a geriatric population and demonstrated to be valid and reliable, it was included in this study for a number of reasons. Firstly, there was no scale available with a similar framework developed for the brain injured population. Secondly, although sharing a similar range of topic areas to the RQ, it takes a different perspective. That is, rather than recording solely whether a problem exists, it asks the carer if dealing with the problem causes strain.

## 4.3.3 The Sample

### 4.3.3(i) Background to the source of the sample

As mentioned in the opening chapter, the study commenced soon after the opening of a national brain injury rehabilitation unit for Scotland. Although neurological rehabilitation had been available in the unit for many years, it was not until 1991 that the Minister for Health designated it as one of three to provide a national service. The Scottish Brain Injury Rehabilitation Service in Edinburgh (SBIRSE) was established to provide early in-patient rehabilitation, principally to the eastern Scottish population. Throughout the study, two other units were in existence in Scotland, a 10 bed specialist inpatient behavioural unit also in Edinburgh, and another unit for inpatient rehabilitation in the west of Scotland. However, the SBIRSE unit was the major centre on the east side of Scotland and indeed received patients from throughout the country. It has close links with the regional neurosurgical service based at the Western General Hospital in Edinburgh.

Patients referred for rehabilitation after the acute medical crisis of their injury has been dealt with, are assessed by medical and nursing staff from the rehabilitation unit. If an in-patient rehabilitation assessment and treatment programme is deemed appropriate, they are transferred to the unit as soon as possible, usually within two months of the date of injury (Pentland and Miller, 1988). Given referral patterns as above, this provided an opportunity to follow up all people who received specialist inpatient rehabilitation in the eastern region.

### 4.3.3(ii) Inclusion and Exclusion Criteria

The sample consisted of patients discharged consecutively over a fifteen month period (October 1992-December 1993). They were included in the sample if they had a traumatic brain injury, or spontaneous haemorrhagic brain injury confirmed by CT scan. Further requirements were that they should consent to a post-discharge visit and live within approximately one hour's travelling distance of Edinburgh. The only exclusion criteria was discharge to another inpatient facility rather than to the community. There were no refusals and this resulted in a sample of 89 patients. Demographic and clinical details regarding the sample are included in Chapter 5.

### 4.3.4 Assessment Procedure

All patients and their relatives meeting the inclusion criteria were asked if they would accept a visit by the researcher at home in the weeks after discharge from hospital. The purpose of the visit was explained as an attempt to find out how the early weeks after discharge had been for the person who had the injury and for their family. If they agreed, the researcher then met with the patient and, where possible, a member of the family in the ward prior to leaving the hospital. A printed sheet was given as a written reminder of information given. This included an independent contact name and phone number in case of any concerns they did not feel able to discuss with the researcher.

A time for the visit was agreed, and it was explained that the researcher would call by phone or write to confirm the appointment closer to the time. Patients, and their relatives where appropriate, were asked to sign a consent form which confirmed the nature of the study and their participation in it. Patients and their carers were assured of the confidentiality of information given, but were asked to allow details pertinent to their care to be passed on to relevant professionals. A copy of the consent form, the information sheet and the appointment confirmation letters are supplied in Appendix (vi), (vii) and (viii) respectively.

All assessments were carried out by the researcher (K.M), with experience as a registered nurse in community health (as a health visitor). In each case, the assessment took place in the patient's home and where possible, another person nominated by the patient, (usually a relative) was asked to be present. Each assessment took approximately one to two hours and consisted of observation of activities complemented by interview data from both the patient and relative.

The outcome measures used in the assessment procedure at six weeks and 15 months post-discharge, are described above and summarised using the appropriate abbreviations in Table 4.3-4.

*Table 4.3-4: Measures recorded at six weeks and 15 months assessments*

| |
|---|
| Barthel Index |
| OPCS Scale |
| FIM |
| FIM+FAM |
| ERSS |
| GOS |
| RQ |
| SF-36 (at 15 months only) |
| Caregiver Strain Index (at 15 months only) |

The FIM+FAM score prior to discharge was also recorded in order to investigate change in level of function in the weeks between discharge and six week follow up. The discharge score was based on the team assessment of the patient and the researcher's discussion with staff and observation of the patient.

### 4.3.5 Data management and Statistical analysis

Data was managed using Paradox Version 4 for Windows, and Excel Version 5.0 for Windows. The data protection act was observed and ethical approval was obtained for the study (Appendix ix). Data was analysed using SPSS Version 6 and Version 7 for Windows. SAS was used for the reliability study of the FIM+FAM.

# FOLLOW-UP OF FUNCTIONAL OUTCOME INTO THE COMMUNITY : RESULTS

This section provides demographic details for the study population as a whole, and where appropriate, a breakdown is provided for TBI and HBI.

## 5.1 Demographic Details

### 5.1.1 Place of residence, age and marital status

The majority of the study sample came from the Lothians and most of those lived in the city of Edinburgh (Table 5.1-1).

*Table 5.1-1: Area of residence at discharge*

| | | Frequency | Percent |
|---|---|---|---|
| | City of Edinburgh | 40 | 44.9 |
| | Fife | 13 | 14.6 |
| | Forth Valley | 9 | 10.1 |
| | South Lothian | 9 | 10.1 |
| | West Lothian | 9 | 10.1 |
| | East Lothian | 6 | 6.7 |
| | Borders | 3 | 3.4 |
| Total | | 89 | 100.0 |

Most patients were male (n=58, 65%), with a greater proportion of males in the TBI group and almost even sex distribution for the HBI group (Table 5.1-2).

*Table 5.1-2: Sex distribution*

| | TBI | | HBI | |
|---|---|---|---|---|
| | n | % | n | % |
| Male | 41 | 75.9 | 17 | 48.6 |
| Female | 13 | 24.1 | 18 | 51.4 |
| Total | 54 | 100 | 35 | 100 |

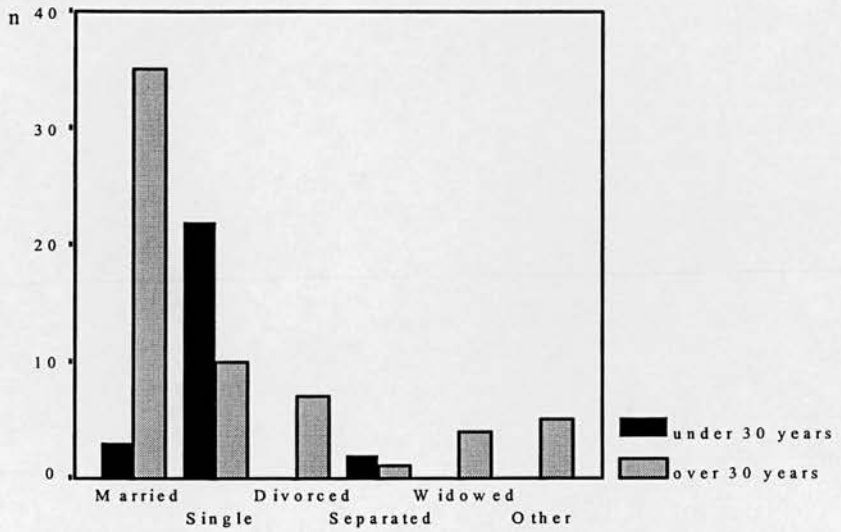
The mean age of the total study sample was 43.9 years, with the TBI population on average 20 years younger than the HBI group (Table 5.1-3).

*Table 5.1-3: Age distribution*

| Type of Brain Injury | N | Mean | Std. Deviation | Minimum | Maximum |
|---|---|---|---|---|---|
| TBI | 54 | 36.02 | 18.34 | 14 | 75 |
| HBI | 35 | 56.03 | 10.63 | 29 | 76 |

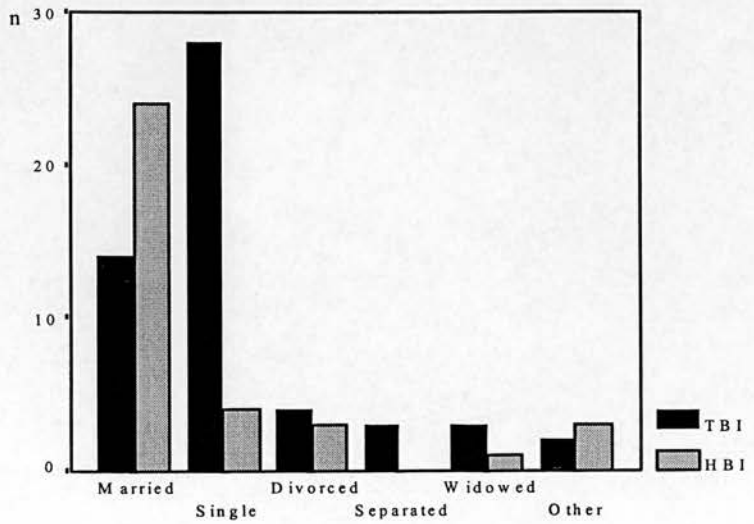
Marital status is shown in Figure 5.1-1 with most patients under 30 years of age single, and the majority over 30 years being married.

*Figure 5.1-1: Marital status by age*




As one might expect from the findings in Table 5.1-3 and Figure 5.1-1, the majority of TBI subjects were single at the time of their injury and most of the HBI group were married (Figure 5.1-2).

*Figure 5.1-2: Marital status by type of injury*



### 5.1.2 Length of stay

The length of stay (LOS) in the acute referring unit varied considerably (Table 5.1-4).

*Table 5.1-4: Length of stay in acute unit (days)*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Median | Minimum | Maximum | 25 | 75 |
| n=89 | 25 | 11 | 135 | 18 | 36 |

Although the median for the TBI group was 28 days (Interquartile range - 1QR=19.75) and for the HBI group 21 days (IQR=10), the difference is not significant (Mann-Whitney U=767.5, p=0.14). The length of stay in the rehabilitation unit also varied considerably (Table 5.1-5).

*Table 5.1-5: Length of stay in rehabilitation unit (days)*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Median | Minimum | Maximum | 25 | 75 |
| n=89 | 28 | 4 | 385 | 15.5 | 53.0 |

The IQR and s.d. highlights that a number of patients stayed considerably longer than the median of 28 days. Eleven cases (12%) stayed longer than 100 days, two of those over 200 days and one over 300 days. The median LOS for the HBI group was the same as for the total population at 28 days (s.d. 47.51 days) compared to 24.5 days (s.d. 67.57 days) for the TBI group. There was no significant difference between the two groups (Mann-Whitney U=762.5, p=0.13).

### 5.1.3 Employment and Social Class

Just over half of those aged under 65 years were actively employed prior to the injury, but 22% of those eligible for work were unemployed excluding students and those retired or unfit (Table 5.1-6) Unemployment was more common in the TBI group ($\chi^2$=4.33, p=0.037)[1].

*Table 5.1-6: Employment status*

| | Type of Brain Injury | | | |
|---|---|---|---|---|
| | TBI | | HBI | |
| | n | % | n | % |
| fulltime | 25 | 46.3 | 10 | 28.6 |
| part-time | 1 | 1.9 | 5 | 14.3 |
| housewife | 2 | 3.7 | 7 | 20.0 |
| student | 9 | 16.7 | - | - |
| retired | 3 | 5.6 | 9 | 25.7 |
| unemployed | 13 | 24.1 | 2 | 5.7 |
| unfit | 1 | 1.9 | 2 | 5.7 |
| Total | 54 | 100.0 | 35 | 100.0 |

[1] All Chi Square calculations for 2x2 tables have utilised Yates correction

The data has also been grouped according to social class using the Standard Occupation Classification (OPCS 1991). Where employment history was not available, the social class of partner or parent has been used (Table 5.1-7).The majority of subjects are in lower economic groups and there is no significant difference in social class between groups ($\chi^2$=5.19, p=0.4) although a greater proportion of the TBI group were in social class 5.

*Table 5.1-7: Social class and type of injury*

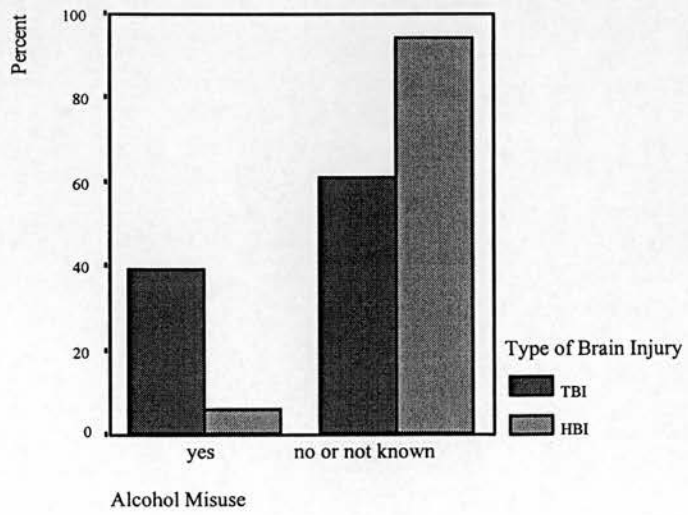
| CLASS | TBI | HBI | Total |
|---|---|---|---|
| 1 | 6 | 2 | 8 |
| 2 | 7 | 6 | 13 |
| 3 (non manual) | 11 | 5 | 16 |
| 3 (manual) | 11 | 10 | 21 |
| 4 | 8 | 9 | 17 |
| 5 | 11 | 3 | 14 |
| Total | 54 | 35 | 89 |

### 5.1.4 Premorbid Health

The majority of patients reported no pre-injury health problems requiring medical care from specialist services. Three had pre-existing serious health concerns necessitating ongoing medical attention. One person had suffered a previous HBI, one had a cardiac condition and one person had long-standing mental health problems for which he had been attending a psychiatric day hospital.

Known alcohol misuse was particularly common in the TBI group with 21 (39%) having an alcohol problem recorded in the medical notes (Figure 5.1-3). The fact that such information is not always available, or sought, means that the information may represent an underestimate of the extent of alcohol misuse.

*Figure 5.1-3: Alcohol misuse*

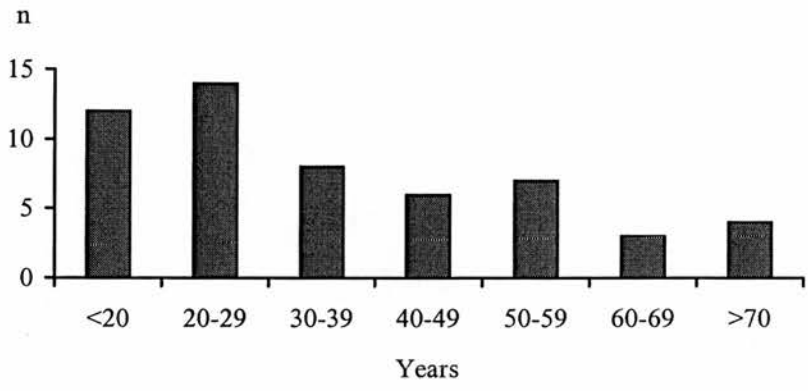


## 5.2 Clinical Features of TBI Group

### 5.2.1 Age

Age distribution for the TBI group is skewed with the majority aged under 30 years (Figure 5.2-1).

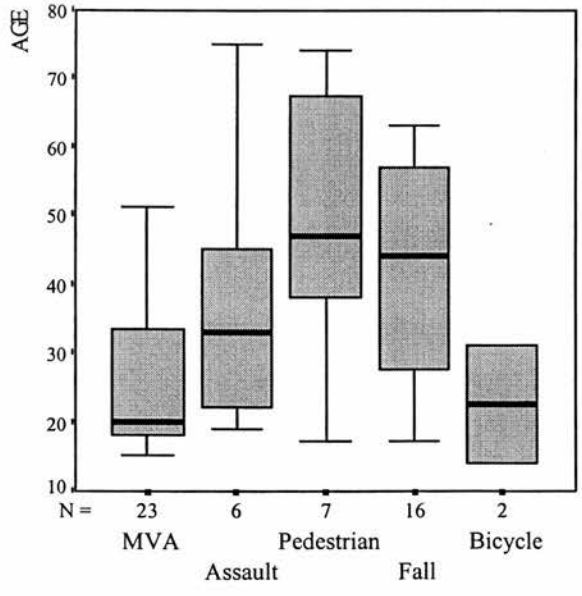
*Figure 5.2-1: Age distribution (TBI)*




### 5.2.2 Cause of TBI

The cause of injury is in keeping with previous studies, with the most common cause being motor vehicle accidents (MVA)(n=23). The second most common cause was falls (n=16) with smaller numbers in other groups. Figure 5.2-2 illustrates the median age, interquartile range and extreme values according to cause of injury.

*Figure 5.2-2: Age distribution by cause of injury*




The MVA group is comprised of younger patients whilst those injured in falls or as pedestrians are older. Kruskal Wallis test shows the difference in age to be significant across the groups ($\chi^2$=11.72 p=0.009).

### 5.2.3 Type of Injury

Nineteen (35%) subjects required surgical intervention for subdural, extradural or traumatic subarachnoid haemorrhage, and 12 (24%) had contusion or haemorrhage not requiring surgery. The remaining 23 (43%) had sustained diffuse axonal injury with no discrete haemorrhage identified by CT or MRI brain scan.

### 5.2.4 Severity of Injury

The majority of patients had their GCS assessed in the acute unit and using the conventional classification, (see Chapter 2), almost two thirds (65%) are categorised as having a severe head injury (Table 5.2-1).

*Table 5.2-1: Severity on GCS*

| | | Frequency | Percent |
|---|---|---|---|
| | Mild | 4 | 7.4 |
| | Moderate | 14 | 25.9 |
| | severe | 33 | 61.1 |
| | Missing | 3 | 5.6 |
| Total | | 54 | 100.0 |

Using PTA, all but two patients were classified as having a severe or very severe injury (Table 5.2-2). For the four patients who were assessed as having a mild injury on their admission GCS, PTA indicated a more severe injury.

*Table 5.2-2: Post Traumatic Amnesia severity group*

| | Frequency | Percent |
|---|---|---|
| Moderate - 1 to 24hours | 2 | 3.7 |
| Severe - 1 to 7 days | 6 | 11.1 |
| Very Severe - 1 week to 4 weeks | 27 | 50.0 |
| Very Severe >4weeks | 19 | 35.2 |
| Total | 54 | 100.0 |

### 5.2.5 Secondary Insults and Complications (TBI)

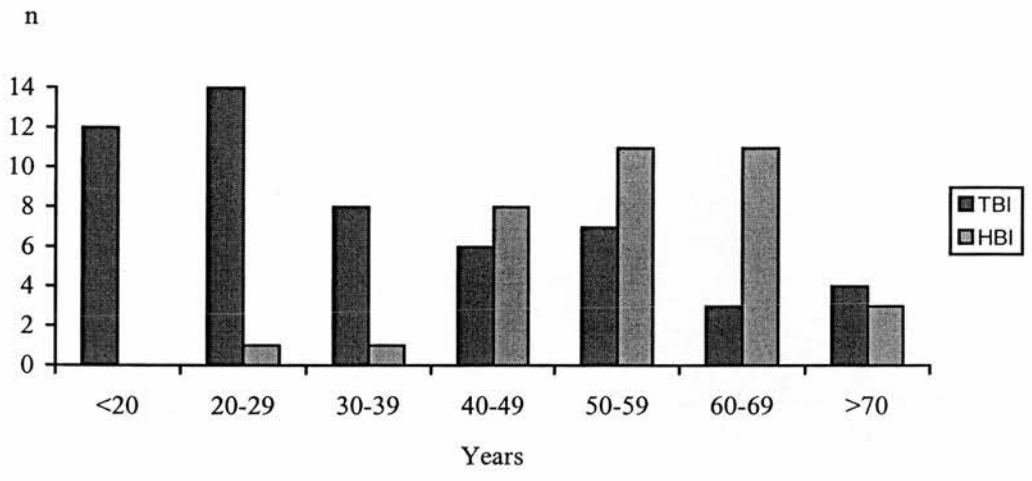
Raised intracranial pressure (ICP) was particularly common with almost one third having ICP monitoring devices inserted. However, it is likely that more of the sample experienced episodes of ICP given that it is a comparatively frequent occurrence after serious brain injury (Pitts and MacIntosh, 1990). Seven people (13%) had early seizures persisting beyond the first 24 hours, and a further two had hydrocephalus.

## 5.3 Clinical Features of HBI Group

### 5.3.1 Age

The age distribution for the HBI group shows the majority of patients were aged over 40 years in contrast with the TBI group (Figure 5.3-1).

*Figure 5.3-1: Age distribution (total population)*




### 5.3.2 Cause of HBI

The majority of HBI were due to subarachnoid haemorrhage resulting from a ruptured cerebral aneurysm (n=22), with two others having aneurysm clipped in the absence of subarachnoid haemorrhage (SAH) (Table 5.3-1).

*Table 5.3-1: Principal condition*

| Type of HBI | n | % |
|---|---|---|
| SAH + clipping of aneurysm | 20 | 57.1 |
| intracerebral haemorrhage ( no surgery) | 5 | 14.3 |
| SAH (no surgery) | 2 | 5.7 |
| aneurysm + clipping (no SAH) | 2 | 5.7 |
| thalamic haemorrhage | 1 | 2.9 |
| midbrain haemangioma | 1 | 2.9 |
| arteriovenous malformation (AVM) - no surgery | 1 | 2.9 |
| SDH + surgery | 1 | 2.9 |
| AVM + surgery | 1 | 2.9 |
| internal capsule haemorrhage | 1 | 2.9 |
| Total | 35 | 100.0 |

Table 5.3-2 shows that of those who had a SAH (n=24), the majority were due to aneurysms of the anterior communicating artery (n=10) or the middle cerebral artery (n=5).

*Table 5.3-2: Location of aneurysm*

| Type of Aneurysm | n | % |
|---|---|---|
| Anterior Comunicating Artery (ACA) | 10 | 41.7 |
| Middle Cerebral Artery (MCA) | 5 | 20.8 |
| Internal Carotid Artery (ICA) | 3 | 12.5 |
| Posterior Inferior Cerebellar Artery (PICA) | 2 | 8.3 |
| Internal Carotid Posterior Communicating Artery (ICPC) | 1 | 4.2 |
| Basilar Artery (BAS) | 1 | 4.2 |
| Subarachnoid Haemorrhage - no aneurysm on CT scan | 2 | 8.4 |
| Total | 24 | 100.0 |

### 5.3.3 Severity of Injury - HBI

In addition to GCS and PTA, the WFNS has been used to measure severity of HBI (as discussed in Chapter 2). The WFNS indicates that the study population were at the more severe end of the spectrum of severity of those presenting at neurosurgical units (O'Sullivan et al, 1996) (Table 5.3-3).

*Table 5.3-3: WFNS Score*

| | n | % |
|---|---|---|
| I | 7 | 20.0 |
| II | 3 | 8.6 |
| III | 11 | 31.4 |
| IV | 3 | 8.6 |
| V | 9 | 25.7 |
| N/A | 2 | 5.7 |
| Total | 35 | 100.0 |

The severity of injury as indicated by the GCS and PTA is shown below (Table 5.3-4).

*Table 5.3-4: Severity on GCS and PTA*

| GCS | Frequency | Percent |
|---|---|---|
| Mild | 13 | 37.1 |
| Moderate | 8 | 22.9 |
| Severe | 10 | 28.6 |
| Missing | 4 | 11.4 |
| Total | 35 | 100.0 |

| PTA | Frequency | Percent |
|---|---|---|
| Moderate - 1 to 24 hours | 7 | 20.0 |
| Severe - 1 to 7 days | 4 | 11.4 |
| Very Severe - 1 week to 4 weeks | 14 | 40.0 |
| Very Severe >4weeks | 9 | 25.7 |
| Unassessable | 1 | 2.9 |
| Total | 35 | 100.0 |

For the 13 people categorised as having a mild injury by the GCS criteria, PTA indicated a greater severity. According to the duration of PTA, five of the 13 would be judged to have moderate injury, the other eight being severe or very severe injuries.

### 5.3.4 Secondary Insults and Complications (HBI)

The majority of this group (n=19, 54%) experienced serious complications during their acute hospital stay. Five (14%) patients sustained intracerebral infarcts as a result of vasospasm, a further five had hydrocephalus requiring insertion of shunts and four (11%) had hydrocephalus managed conservatively. Five people had seizures after 24 hours but within the first week.

## 5.4 Six week follow-up assessment

The majority of patients (n=82, 92%) were seen at home six weeks after discharge from inpatient rehabilitation. However, in seven cases, there was a delay due to difficulties in arranging a suitable time to visit but all were seen within 8 weeks. As a consequence, the length of time from injury to assessment varied as shown in Table 5.4-1.

*Table 5.4-1: Length of time from injury to assessment*

| | N | Median | Std. Deviation | Minimum | Maximum | Percentiles 25 | 75 |
|---|---|---|---|---|---|---|---|
| Time after Injury (Days) | 89 | 86.00 | 80.68 | 50 | 527 | 70.00 | 116.00 |

## 5.5 Profile of function at six weeks post discharge

As the majority of data is at the ordinal level of measurement, non parametric statistical presentation of the results is most appropriate. Further, it is argued elsewhere that items on such ordinal scales are most appropriately viewed as a profile of the individual's function (Pentland and McPherson 1994). However, in order to compare the measures, a pragmatic approach is taken and therefore for some analysis, the data has been summated.

### 5.5.1 Total Scores

Each of the total scores in the measures correlates in a highly significant manner to the others as shown in (Table 5.5-1).

*Table 5.5-1: Spearman rank correlation[2] - total scores*

| | Barthel | OPCS - OSS | FIM | FIM+ FAM | ERSS | GOS |
|---|---|---|---|---|---|---|
| Barthel | 1.00 | -.63 ** | .75 ** | .66 ** | -.67 ** | .44 ** |
| OPCS - OSS | -.63 ** | 1.00 | -.86 ** | -.86 ** | .86 ** | -.63 ** |
| FIM | .75 ** | -.86 ** | 1.00 | .97 ** | -.87 ** | .65 ** |
| FIM+FAM | .66 ** | -.86 ** | .97 ** | 1.00 | -.89 ** | .68 ** |
| ERSS | -.67 ** | .86 ** | -.87 ** | -.89 ** | 1.00 | -.77 ** |
| GOS | .44 ** | -.63 ** | .65 ** | .68 ** | -.77 ** | 1.00 |

**. Correlation is significant at the .01 level (2-tailed).

As stated in Chapter 2, the scoring of the OPCS and ERSS scores move in the opposite direction to the GOS, Barthel, FIM and FIM+FAM. Higher scores in the latter scales indicate better levels of function. This shows in the negative correlation coefficients above. The median total scores are considered in Table 5.5-2 with the possible scores highlighted in the shaded area.

*Table 5.5-2: Descriptive total scores on measures*

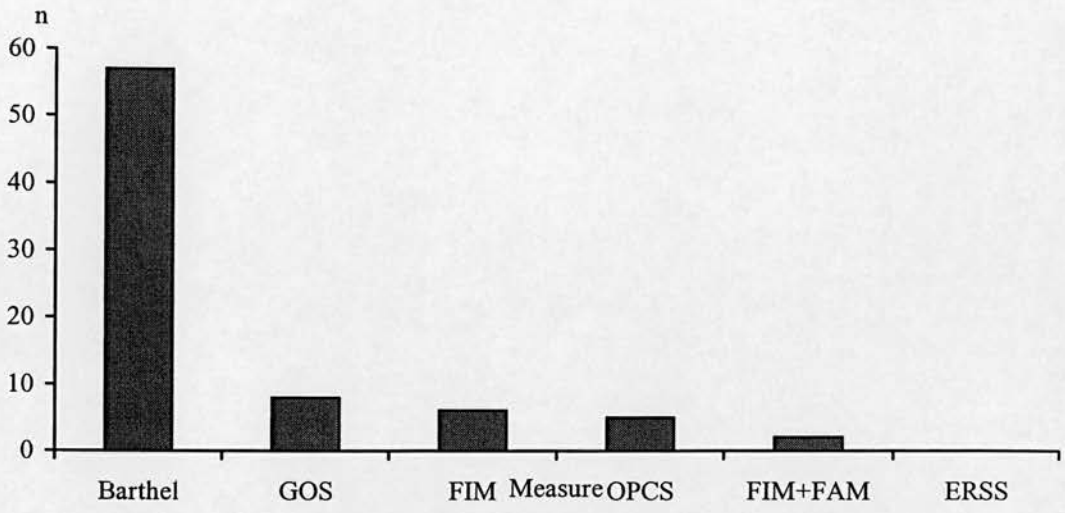
| | | Barthel | OPCS | FIM | FIM+FAM | ERSS | GOS |
|---|---|---|---|---|---|---|---|
| | Best Possible Score | 20 | .0 | 126 | 210 | 28 | 5 |
| | Worst Possible Score | 0 | 21.4 | 18 | 30 | 0 | 1[a] |
| Mean | | 18.57 | 7.07 | 113.46 | 183.09 | 11.76 | 3.56 |
| Median | | 20.00 | 6.50 | 118.00 | 189.00 | 11.00 | 3.00 |
| Std. Deviation | | 3.04 | 5.02 | 14.49 | 23.73 | 4.72 | .67 |
| Skewness | | -3.05 | .54 | -2.67 | -1.94 | .45 | .80 |
| Kurtosis | | 10.29 | -.29 | 9.19 | 5.78 | -.21 | -.47 |
| Minimum | | 3.00 | .00 | 39.00 | 69.00 | 3.00 | 3.00 |
| Maximum | | 20.00 | 19.05 | 126.00 | 210.00 | 25.00 | 5.00 |
| Percentiles | 25 | 19.00 | 3.00 | 109.50 | 173.00 | 8.00 | 3.00 |
| | 75 | 20.00 | 10.20 | 123.00 | 199.00 | 15.00 | 4.00 |

a. In this study, the worst possible score on GOS=3

The median score of the Barthel equates with the highest level of function for that scale. Further, the IQR indicates that most patients are indeed classified at the highest level of function on this measure. There was no significant difference between the TBI and HBI groups on the total scores of any of the measures. Figure 5.5-1 indicates the number in the study population who are at the ceiling (best level of function) on each measure.

[2] For ease, significance values in all correlation matrices is noted at the level of $p<0.05$ or $p< 0.01$.

*Figure 5.5-1: Number of patients at ceiling level on measures*




In order to further explore the total scores, it may be useful to transpose each total into a percentage disability score as has been done elsewhere (Hunter, 1996). This allows totals to be compared more easily as each is rated out of 100 where high scores indicate high levels of deficit (Table 5.5-3). Where the best possible score on a measure is not zero, (as in the FIM or the FIM+FAM ) this has been taken into account when calculating the percentage score.

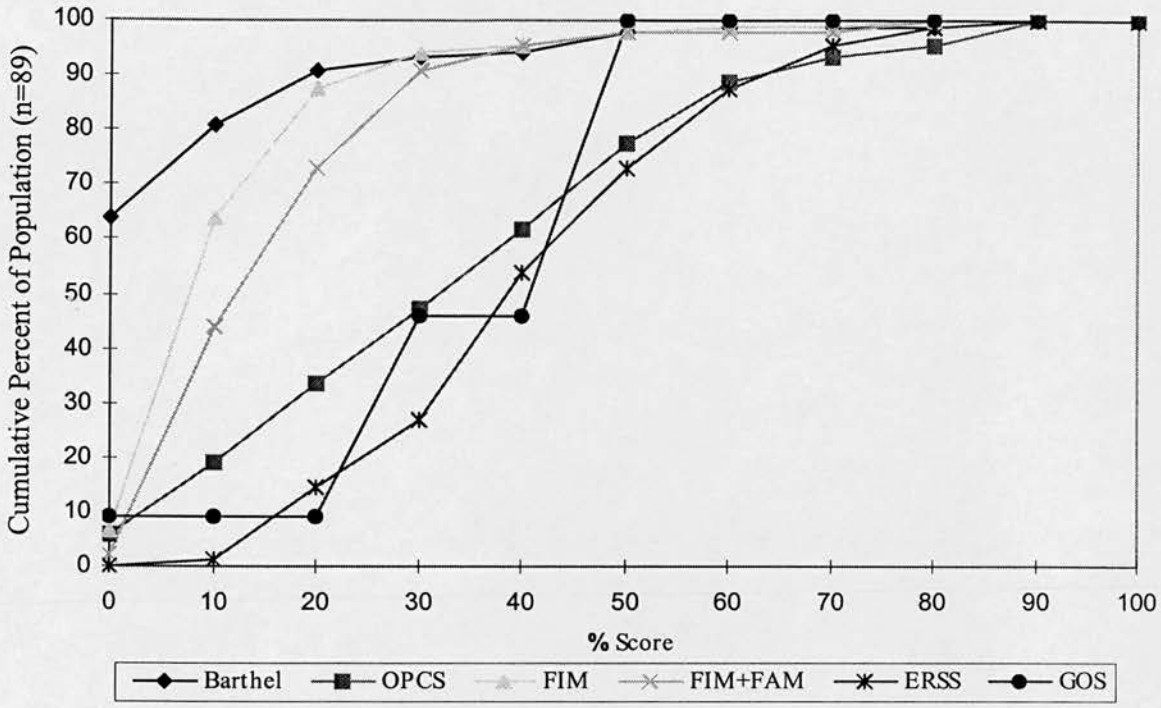
*Table 5.5-3: Percentage deficit on each measure*

| | | % Score Barthel | % Score OPCS | % Score FIM | % Score FIM+FAM | % Score ERSS | % score GOS |
|---|---|---|---|---|---|---|---|
| Mean | | 7.13 | 33.03 | 11.61 | 14.94 | 42.01 | 35.80 |
| Median | | .00 | 30.37 | 7.41 | 11.67 | 39.29 | 50.00 |
| Std. Deviation | | 15.19 | 23.45 | 13.42 | 13.19 | 16.86 | 16.35 |
| Skewness | | 3.05 | .54 | 2.68 | 1.94 | .45 | -.72 |
| Kurtosis | | 10.29 | -.29 | 9.20 | 5.77 | -.21 | -.49 |
| Minimum | | .00 | .00 | .00 | .00 | 10.71 | .00 |
| Maximum | | 85.00 | 89.02 | 80.56 | 78.33 | 89.29 | 50.00 |
| Percentiles | 25 | .00 | 14.02 | 2.78 | 6.11 | 28.57 | 25.00 |
| | 75 | 5.00 | 47.66 | 15.28 | 20.56 | 53.57 | 50.00 |

Although caution must be exercised when interpreting such analysis, it is interesting to note a disparity in percentage disability levels on the GOS, the FIM and the FIM+FAM . The FIM, FIM+FAM and GOS share the conceptual basis of measuring dependency albeit in functions other than ADL and mobility as in the Barthel. However, the GOS identifies a higher average percentage level of disability than either the FIM or indeed the FIM+FAM given that only one score (GOS=3), can be given to a person who is dependent in any activity whilst a range of scores is possible for both the other measures. This is further

examined in Figure 5.5-2 where the score on each measure is expressed in relation to the cumulative percentage of the study group.

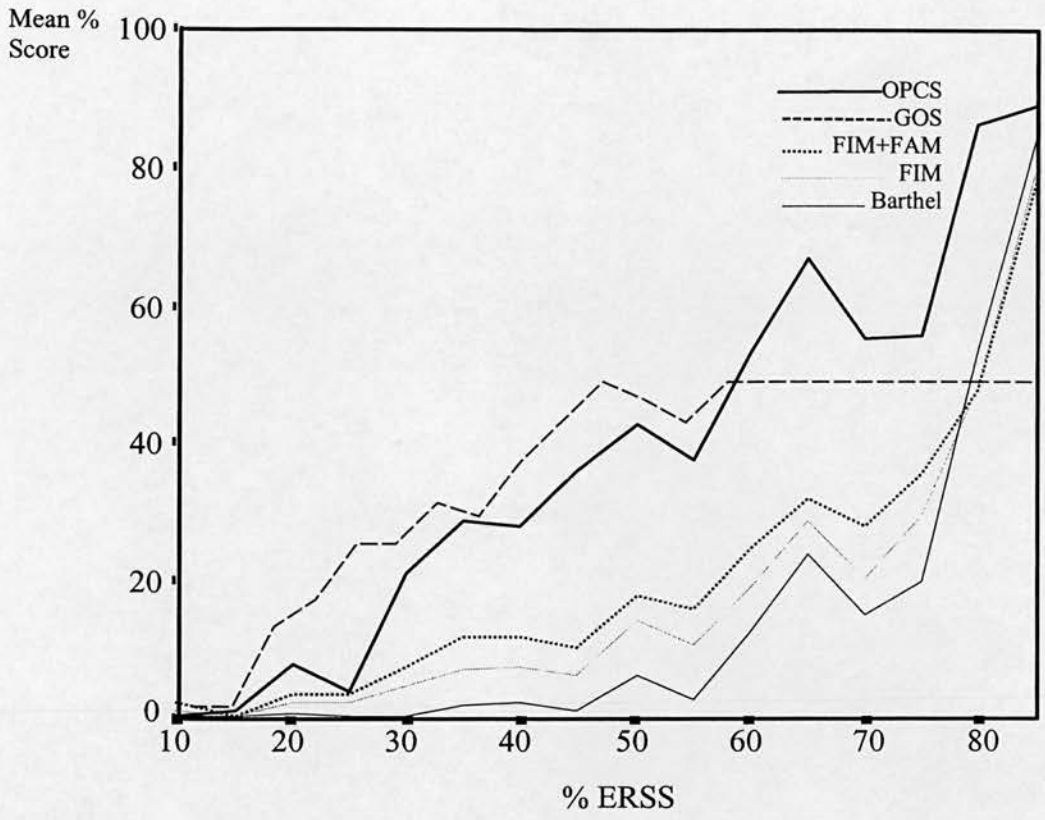
*Figure 5.5-2: Scores for cumulative percentage of group*




It can be seen that over 60% of the group scored 0% on the Barthel as expected from the findings in Figure 5.5-1 with the anticipated smaller proportions scored at 0% in the other measures. However, a far steeper rise is noted for the FIM and the FIM+FAM than for the GOS or the OPCS. Even by 20% deficit, 87% of the population are accounted for on the FIM and 73% on the FIM+FAM. The rise is much more gradual in the other measures with 33% on the OPCS and 14% on the ERSS. It also can be seen that on using the GOS, the total population is accounted for by 50% deficit as none of the population were in a vegetative state, nor had anyone died.

The ERSS was described in the methods section as having a broader conceptual basis than the disability measures, that of approximating handicap. Therefore, the relationship between the percentage disability measures and the percentage ERSS score is explored in Figure 5.5-3.

*Figure 5.5-2: ERSS versus disability measures*




The Barthel can be seen to remain at 0% 'disability' until the ERSS score is almost at 50%. On the other hand, the GOS has not discriminated at higher levels of dysfunction on the ERSS as only three of the five levels on the GOS are utilised in a population that survives beyond persistent vegetative state.

In order to examine the nature of disabilities, subscales on each measure have been examined (other than the GOS which cannot be divided in this way).

## 5.5.2 Subscales and Item Scores

### 5.5.2(i) Barthel Index

The median scores on the Barthel ADL and mobility scales were both at the ceiling level. The IQR and s.d. for ADL were (1, 1.67) and Mobility (0, 1.74) indicating very little spread of scores over the 20 point range possible in this patient population. The median scores by type of brain injury were the same although the distribution of scores wider in the HBI group as shown in Table 5.5-4.

Table 5.5-4: Barthel Scores by type of brain injury

| | | n | Mean | Median | Std. Deviation | Minimum | Maximum | Percentiles 25 | 75 |
|---|---|---|---|---|---|---|---|---|---|
| TBI | Total | 54 | 19.11 | 20 | 1.84 | 10 | 20 | 19 | 20 |
| | Mobility | 54 | 7.67 | 8 | .99 | 2 | 8 | 8 | 8 |
| | Personal Care | 54 | 11.44 | 12 | 1.00 | 8 | 12 | 11 | 12 |
| HBI | Total | 35 | 17.74 | 20 | 4.18 | 3 | 20 | 17 | 20 |
| | Mobility | 35 | 6.80 | 8 | 2.29 | 0 | 8 | 7 | 8 |
| | Personal Care | 35 | 11.17 | 12 | 2.50 | 3 | 20 | 11 | 12 |

### 5.5.2(ii) FIM+FAM

Whilst keeping in mind the caveat expressed in the opening paragraph of Section 5.5, the 30 items of the FIM+FAM have been considered as subscales of items belonging to one scale (McPherson et al 1997). Table 5.5-5 illustrates the grouping of items. Rasch analysis has suggested keeping the two continence items separate to other ADL items (Whalley et al 1996).

*Table 5.5-5: FIM+FAM subscales (Italics* indicates FAM items)*

**Self Care**
*swallowing**
feeding
grooming
bathing
dress-upper
dress-lower
toileting

**Mobility**
**Transfers**
bed/chair
toilet
bath
*car transfers**

**Communication**
comprehension
expression
*reading**
*writing**
*speech intelligibility**

**Cognitive Function**
problem solving
memory
*orientation**
*attention**
*safety judgement**

**Continence**
bladder
bowel

**Locomotion**
walk/wheel
stairs
*community mobility**

**Psychosocial**
social interaction
*emotion**
*adjustment to limits**
*employability**

Table 5.5-6 shows the central tendency and spread of scores in the subscales.

*Table 5.5-6: Descriptive data on FIM+FAM subscales*

| | | ADL | Cont-inence | Transfers | Loco-motion | Commun-ication | Psycho-social | Cognition |
|---|---|---|---|---|---|---|---|---|
| Best Possible Score | | 49 | 14 | 28 | 21 | 35 | 28 | 35 |
| Worst Possible Score | | 7 | 2 | 4 | 3 | 5 | 4 | 5 |
| Mean | | 46.49 | 13.45 | 25.49 | 17.22 | 31.08 | 21.98 | 27.37 |
| Median | | 49 | 14 | 28 | 18 | 32 | 22 | 28 |
| S.D. | | 4.92 | 1.59 | 4.77 | 4.08 | 4.10 | 3.95 | 5.31 |
| Min | | 21 | 6 | 4 | 3 | 11 | 11 | 11 |
| Percentiles | 25 | 45 | 14 | 25 | 16 | 30 | 20 | 23 |
| | 75 | 49 | 14 | 28 | 20 | 34 | 25 | 32 |

The majority of the group were not dependent in self care as measured by the FIM+FAM. However, the spread of scores in ADL and all subscales other than continence (illustrated by the interquartile range) show the measure is capable of highlighting functional problems beyond that of the Barthel. There is no difference in subscale scores between the TBI and HBI group.

The subscales on the FIM+FAM were all significantly correlated to one another (Table 5.5-7).

*Table 5.5-7: Relationship between the FIM+FAM subscales*

| Spearman's rho | ADL | Continence | Transfers | Loco-motion | Commun-ication | Psycho-social | Cognition |
|---|---|---|---|---|---|---|---|
| ADL | | .48** | .81** | .72** | .39** | .46** | .41** |
| Continence | .48** | | .56** | .46** | .43** | .35** | .33** |
| Transfers | .81** | .56** | | .79** | .41** | .45** | .41** |
| Locomotion | .72** | .46** | .79** | | .53** | .61** | .60** |
| Communication | .39** | .43** | .41** | .53** | | .75** | .76** |
| Psychosocial | .46** | .35** | .45** | .61** | .75** | | .87** |
| Cognition | .41** | .33** | .41** | .60** | .76** | .87** | |

**. Correlation is significant at the .01 level (2-tailed).

Although all significant, the coefficients indicate that the seven subscales may potentially be classified as two constructs. The first group of items relating most strongly are ADL and the two mobility subscales, and the second group being items of Communication, Psychosocial Function and Cognitive Function. Factor Analysis was used to explore this further (Table5.5-8).

*Table 5.5-8: Factor analysis of FIM+FAM subscales*

| | FACTOR 1 | FACTOR 2 |
|---|---|---|
| ADL | .88 | -.36 |
| Continence | .76 | -.40 |
| Transfers | .89 | -.40 |
| Locomotion | .89 | -.16 |
| Communication | .80 | .30 |
| Psychosocial | .73 | .61 |
| Cognition | .77 | .57 |
| Eigen Value | 4.70 | 1.26 |
| Variance Accounted for | 67.1% | 17.9% |

The factor loadings indicate that the first factor comprises all subscales. The second factor comprises the interaction between Cognitive / Psychosocial / Communication on one hand, and the ADL, Continence and Mobility subscales on the other. Two new variables can therefore be created using the weightings in Table 5.5-8, and a ranked correlation of these variables and the FIM+FAM total is shown in Table 5.5-9.

*Table 5.5-9: Relationship between the FIM+FAM Factors produced by Factor analysis*

| Spearman's rho | Factor 1 | Factor 2 |
|---|---|---|
| Factor 1 | | .41** |
| Factor 2 | .41** | |
| FIM+FAM Total | .99** | .44** |

**. Correlation is significant at the .01 level (2-tailed).

Although using these two new variables is the most strictly 'statistical' approach, the results do suggest that a pragmatic way forward may be to consider the FIM+FAM score as two sub-totals - one of 'Physical Function' (ADL, Continence and Mobility) and one of 'Psychological Function' (Cognitive Function, Psychosocial Function and Communication). To that end, the relationship of these subtotals to the FIM+FAM total score has also been explored in Table 5.5-10.

*Table 5.5-10: Relationship between the two FIM+FAM factors identified*

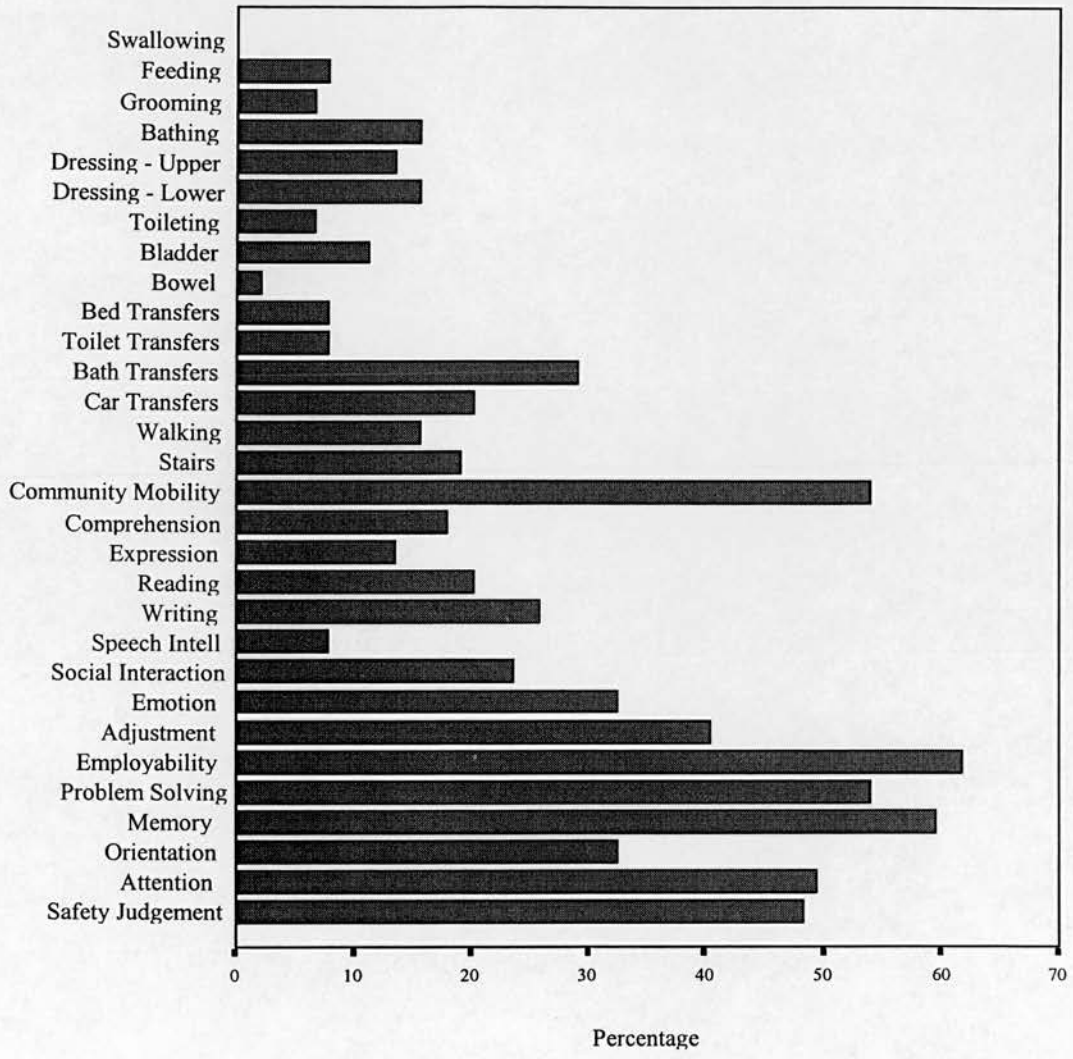
| Spearman's rho | Physical Function | Psychological Function |
|---|---|---|
| Physical Function | | .59** |
| Psychological Function | .59** | |
| FIM+FAM Total | .82** | .93** |

**. Correlation is significant at the .01 level (2-tailed).

The relationship between the two groups of variables was significant, but each related in a far stronger way to the total score. Indeed, 'Psychological Functioning' showed the strongest level of association with the total score. As with the total score and the subscales, there was no significant difference in these two dimension scores between the TBI and HBI groups.

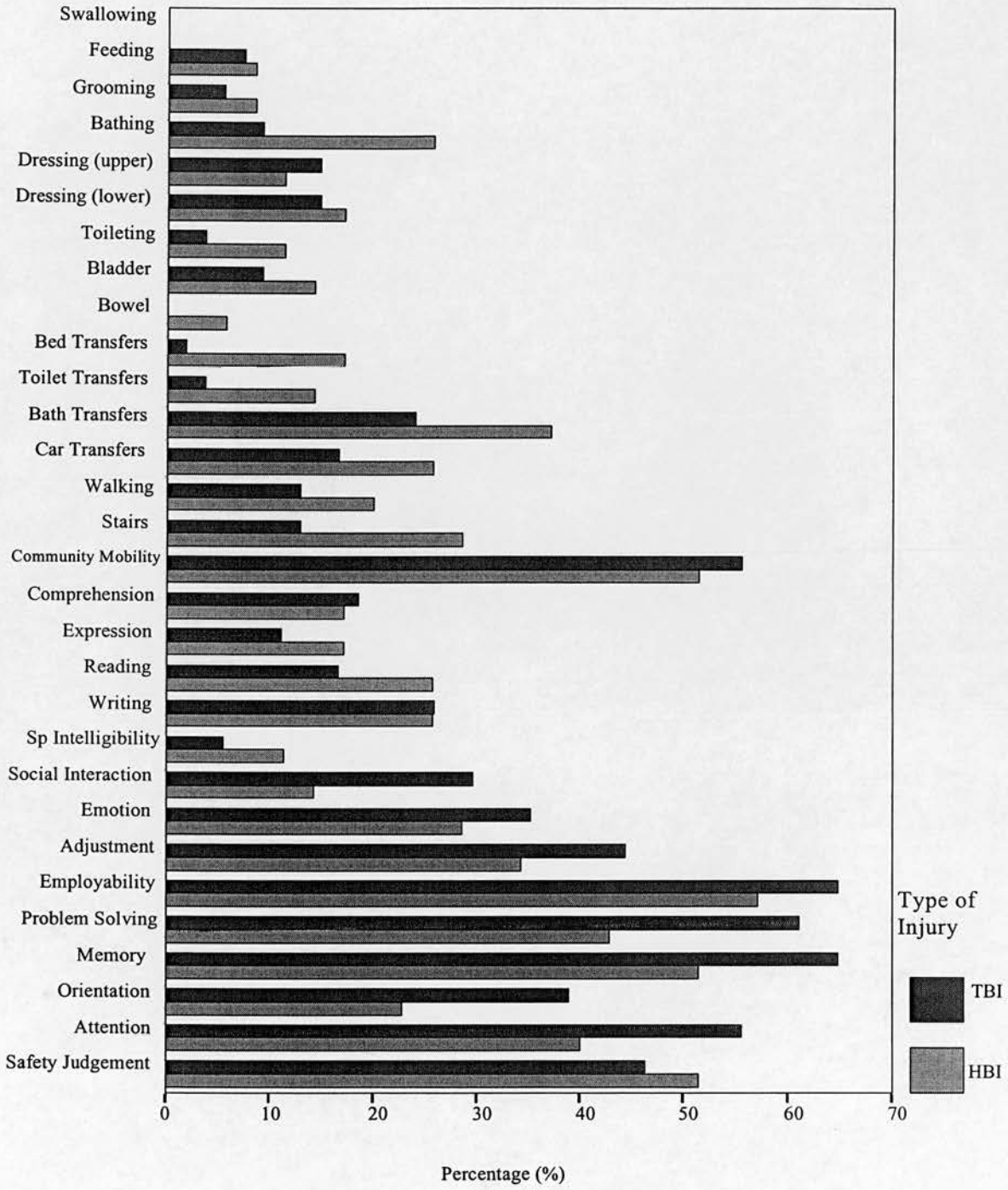
Another way to use the FIM+FAM information to describe the disability more fully, is perhaps, to establish the proportion of people requiring help or supervision (a score of 5 or less) on each item. Over half the group required assistance for function in community mobility, problem solving, memory, adjustment to limits and employability (Figure 5.5-4).

*Figure 5.5-3: Percentage of patients requiring help on individual FIM+FAM items*




When examined by type of brain injury (Figure 5.5-5), a greater percentage of those who had an HBI required assistance with ADL activities. On the other hand, a greater proportion with TBI required assistance with memory, attention and orientation.

*Figure 5.5-4: Percentage of patients requiring help on individual FIM+FAM items by injury*




There is a trend for the HBI group to have required more help in items of Physical Functioning and the TBI in Psychological Functioning although the differences were only significant for two items (Table 5.5-11).

*Table 5.5-11: Difference in help or supervision according to type of injury*

| | Mann-Whitney U | Sig. (2-tailed) |
|---|---|---|
| Bathing | 774.00 | .045 |
| Toilet Transfers | 783.00 | .032 |

In both these cases, the HBI group required more assistance than the TBI. Such findings must be considered cautiously as the chance of at least one Type I error is almost 80% given the multiple testing. In effect, any difference between the two groups appeared to be marginal.

### 5.5.2(iii) OPCS Scale

Although the OPCS scale has 13 dimensions, the Overall Severity Score (OSS) is calculated from the three worst scores (as described in Chapter 4). Table 5.5-12 shows the level to which each dimension contributes to the overall score.

*Table 5.5-12: Dimensions which contributed to OPCS Overall Severity Score (OSS)*

| OPCS (OSS-1) | n | OPCS (OSS-2) | n | (OPCS (OSS-3) | n |
|---|---|---|---|---|---|
| intellectual function (Intell func) | 35 | behaviour | 18 | communication | 9 |
| locomotion | 21 | locomotion | 17 | intell func | 8 |
| behaviour | 7 | intell func | 13 | personal care | 7 |
| sight | 5 | personal care | 6 | reaching | 7 |
| consciousness | 4 | dexterity | 5 | behaviour | 6 |
| reaching | 4 | communication | 2 | locomotion | 6 |
| personal care | 3 | hearing | 2 | consciousness | 3 |
| dexterity | 2 | consciousness | 1 | continence | 3 |
| hearing | 2 | continence | 1 | dexterity | 2 |
| continence | 1 | sight | 1 | sight | 2 |
| communication | - | reaching | - | hearing | 1 |

The dimensions which contributed most frequently to the OSS were Intellectual Function (n=56), Locomotion (n=38), Behaviour (n=31) and Personal Care (n=13). The median scores for these OPCS subscales are shown in Table 5.5-13.

*Table 5.5-13: OPCS dimension scores*

| | | Intellectual Function | Locomotion | Behaviour | Personal Care |
|---|---|---|---|---|---|
| | Best Possible Score | .0 | .0 | .0 | .0 |
| | Worst Possible Score | 13.0 | 11.5 | 10.5 | 11.0 |
| Mean | | 3.63 | 2.64 | 1.34 | 1.46 |
| Median | | 3.50 | .50 | .50 | .00 |
| Std. Deviation | | 3.01 | 3.37 | 1.90 | 2.87 |
| Minimum | | .00 | .00 | .00 | .00 |
| Maximum | | 13.00 | 11.50 | 7.50 | 11.00 |
| Percentiles | 25 | .00 | .00 | .00 | .00 |
| | 75 | 6.00 | 4.00 | 1.50 | 1.00 |

The OPCS's ability to discriminate disability in this population was particularly evident in the dispersion of scores in intellectual function and locomotion. However Table 5.5-14 shows that a number of other dimensions correlate significantly to the OSS.

*Table 5.5-14: Correlation between OPCS Overall Severity Score and dimensions*

| Dimension | Spearman Rank Correlation | p (2-tailed) |
|---|---|---|
| Locomotion | .65 | <0.001 |
| Reaching and Stretching | .47 | <0.001 |
| Dexterity | .50 | <0.001 |
| Personal Care | .69 | <0.001 |
| Continence | .42 | <0.001 |
| Sight | .11 | .308 |
| Hearing | .09 | .395 |
| Communication | .52 | <0.001 |
| Behaviour | .46 | <0.001 |
| Intellectual Function | .74 | <0.001 |
| Consciousness | .29 | .005 |
| Eating, Drinking and Digestion | -.05 | .657 |
| Disfigurement | .33 | .002 |

Although the HBI group appeared to have greater levels of dysfunction in locomotor and personal care dimensions, these differences were not statistically significant. However, the TBI group had a significantly greater level of dysfunction in behaviour and consciousness on the OPCS (Table 5.5-15). There is a 50% chance that one of these findings is a Type I error due to the number of tests performed.

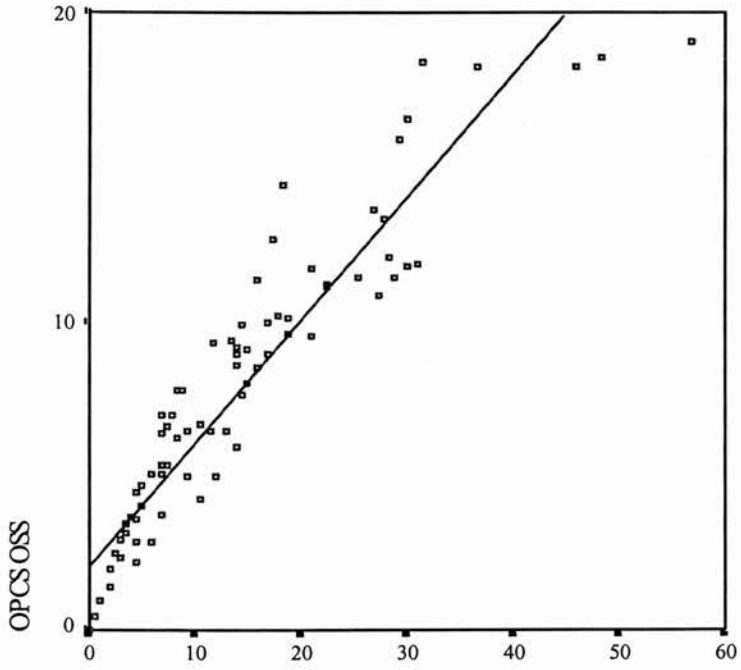
*Table 5.5-15: Difference in OPCS score according to type of injury*

| | Mann-Whitney U | Sig. (2-tailed) |
|---|---|---|
| Behaviour | 702.00 | .032 |
| Consciousness | 822.50 | .028 |

Given that information about the nature of the disability is lost when only considering the total score on the FIM+FAM, it may be valuable to consider whether the calculation of the OSS suggested by the originators of the OPCS is satisfactory in this population (Martin et al. 1988).

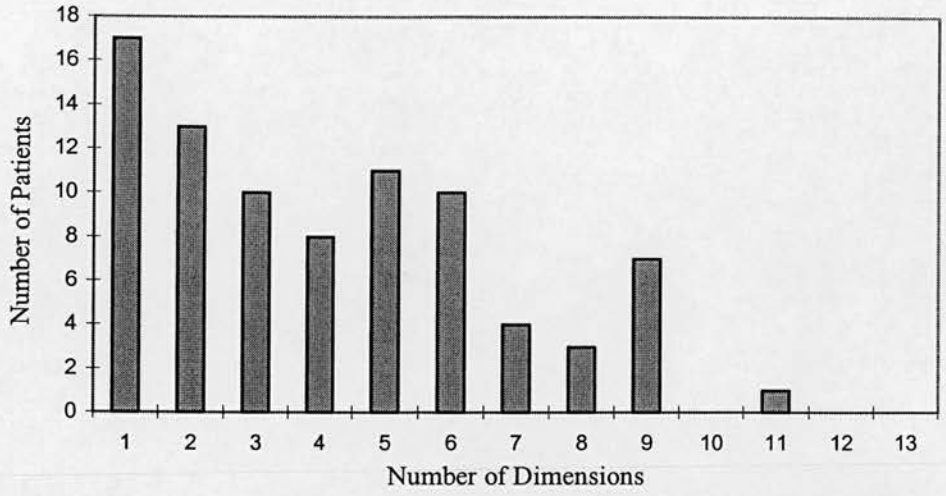
Figure 5.5-5 shows a plot of the OPCS OSS (the three worst scores) against the combined total of the 13 dimension scores added together.

*Figure 5.5-5: OPCS OSS versus total of all OPCS dimensions*



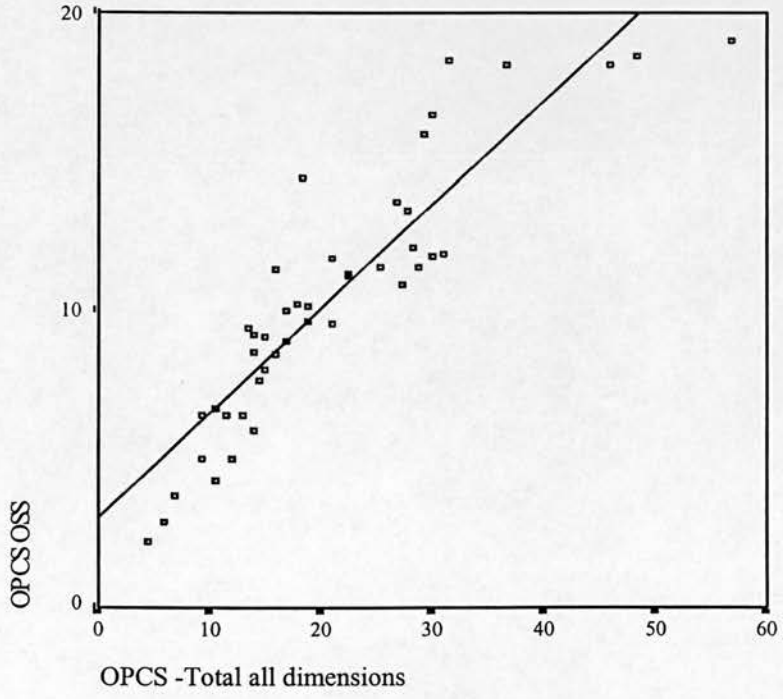

There is a very strong relationship between the two total scores (Spearmans rho = 0.97) and it appears that for the majority of patients, the OSS and total of all dimensions are ranked similarly. This may be explained in part due to the number of dimensions where scores are above zero as shown in Figure 5.5-7.

*Figure 5.5-6: Number of OPCS dimensions greater than zero for each patient*




Just under half the group (n=44, 49%) are scored as having a disability in four or more dimensions on the OPCS. To determine whether the OSS reflects the actual range of severity in multiple disability, a scatterplot shows just those patients (n=44) scoring in more than three dimensions (Figure 5.5-8).

*Figure 5.5-7: OPCS OSS versus total of all OPCS dimensions for those with multiple disabilities*




The correlation coefficient for the totals has remained strong (Spearmans rho=0.94) and the correlation between each OPCS dimension and the two totals were very similar (Table 5.5.16).

*Table 5.5-16: Correlation between OPCS OSS and dimensions*

| Spearman's Rank Correlation | OPCS OSS | OPCS -Total all Dimensions |
|---|---|---|
| Locomotion | .65** | .70** |
| Reaching and Stretching | .47** | .56** |
| Dexterity | .50** | .58** |
| Personal Care | .69** | .78** |
| Continence | .42** | .44** |
| Sight | .11 | .15 |
| Hearing | .09 | .17 |
| Communication | .52** | .56** |
| Behaviour | .46** | .49** |
| Intellectual Function | .74** | .71** |
| Consciousness | .29** | .27* |
| Eating, Drinking and Digestion | -.05 | .02 |
| Disfigurement | .33** | .37** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

### 5.5.2(iv) ERSS

The ERSS total is made up of four subscales (as described in Chapter 4). One of these, Support, relates to dependency but, in a global sense as opposed to solely in relation to ADL. The range of scores is shown in Table 5.5-17.

*Table 5.5-17: ERSS subscale scores*

| | | Support | Activity / Inactivity | Social Isolation | Effect of Symptoms |
|---|---|---|---|---|---|
| | Best Possible Score | 0 | 0 | 0 | 0 |
| | Worst Possible Score | 7 | 7 | 7 | 7 |
| Mean | | 2.76 | 3.67 | 2.13 | 3.20 |
| Median | | 3.00 | 3.00 | 2.00 | 3.00 |
| Std. Deviation | | 1.48 | 1.20 | 1.32 | 1.31 |
| Minimum | | 1 | 1 | 0 | 1 |
| Maximum | | 6 | 7 | 5 | 7 |
| Percentiles | 25 | 1.00 | 3.00 | 1.00 | 2.00 |
| | 75 | 4.00 | 5.00 | 3.00 | 4.00 |

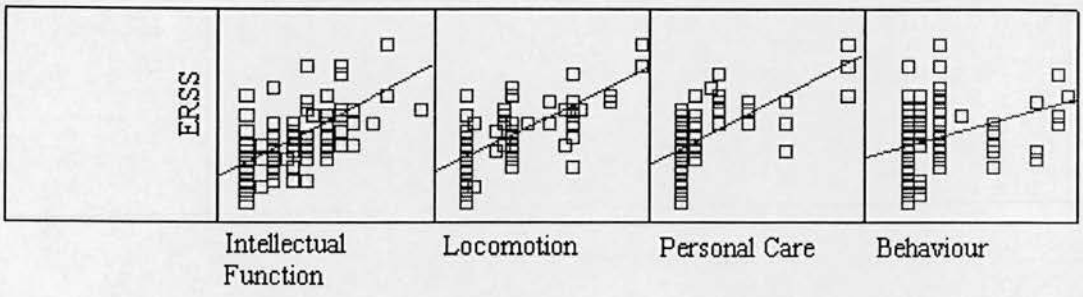
The median of each subscale was in the middle of the range of possible scores and, the dispersion of results indicated that each of the subscales has contributed to the total score to a similar degree. There was no significant difference in ERSS dimension scores for the HBI or TBI group.

## 5.6 Relationship between Handicap (ERSS) and Disability (OPCS)

In terms of the disability measures, the OPCS has been shown to have a linear relationship with the ERSS along the whole range of scoring with a Spearman correlation coefficient of 0.86. It is therefore chosen as the disability measure to compare with outcome in terms of medicosocial dysfunction as measured on the ERSS.

In order to explore the relationship between the two measures, the four OPCS dimensions which contributed most to the Overall Severity Score (OPCS-OSS) have been examined in relation to the ERSS. Figure 5.6-1 shows that each of the OPCS dimensions related in a linear fashion to the ERSS total score, although at lower OPCS scores, a range of ERSS scores has been found.

*Figure 5.6-1: ERSS versus OPCS dimension scores*




In order to investigate the relative contribution that each of these disabilities has made towards the ERSS total, linear regression was carried out. Table 5.6-1 shows that Locomotion and Personal Care were correlated strongly.

*Table 5.6-1: Relationship between OPCS dimensions*

| Spearman's rho | Personal Care | Behaviour | Intellectual Function | Locomotion |
|---|---|---|---|---|
| Personal Care | | .21* | .39** | .76** |
| Behaviour | .21* | | .46** | .13 |
| Intellectual Function | .39** | .46** | | .34** |
| Locomotion | .76** | .13 | .34** | |

*. Correlation is significant at the .05 level (2-tailed).

**. Correlation is significant at the .01 level (2-tailed).

Further, Table 5.6-2 indicates that collinearity between the two OPCS variables and the ERSS exists (indicated by the high variance proportions - shaded cells). For this reason, personal care was excluded from the regression analysis.

*Table 5.6-2: Collinearity of OPCS dimensions in relation to ERSS*

| | | | Variance Proportions | | | |
|---|---|---|---|---|---|---|
| | Eigenvalue | (Constant) | Personal Care | Behaviour | Intellectual Function | Locomotion |
| 1 | 3.31 | .02 | .02 | .02 | .02 | .02 |
| 2 | .93 | .02 | .12 | .21 | .02 | .05 |
| 3 | .39 | .36 | .08 | .64 | .04 | .00 |
| 4 | .21 | .42 | .00 | .12 | .92 | .04 |
| 5 | .15 | .18 | .78 | .00 | .00 | .89 |

Table 5.6-3 indicates that each variable contributed to the ERSS score to a significant degree even when the other variables were taken into account.

*Table 5.6-3: Significance of contribution of OPCS dimensions to ERSS*

| Standardized Coefficients | Beta | t | Sig. |
|---|---|---|---|
| (Constant) | | 15.89 | <0.001 |
| Locomotion | .62 | 10.49 | <0.001 |
| Intellectual Function | .37 | 5.72 | <0.001 |
| Behaviour | .17 | 2.77 | .007 |

*** Correlation is significant at the level of 0.001 (2-tailed)

A regression model using only OPCS Locomotion accounted for 55% of the variance in the ERSS and allows prediction of the ERSS score within three points. Including only Intellectual Function explained 39% of the variance in the ERSS score while a model using both, accounted for 72% of the variance (Table 5.6-4). The score in the Behaviour dimension accounts for 10% of the variance in ERSS score but explains little of the variance once Locomotion and Intellectual Function have been included.

*Table 5.6-4: Linear regression ANOVA of ERSS using OPCS dimensions*

| Model | Variables Entered | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | Locomotion | .545 | .540 | 3.20 |
| 2 | Intellectual Function | .716 | .710 | 2.54 |
| 3 | Behaviour | .740 | .730 | 2.45 |

At six weeks after discharge from in-patient rehabilitation, disability in locomotor function and intellectual function explained the greater proportion of the variance in the ERSS score, leaving around 30% to be explained by variables other than disability.

## 5.7 Relationship of injury severity to outcome at six weeks

The relationship between severity of injury and outcome was explored using non-parametric analysis of variance. Scores did not differ according to the different GCS severity categories but there was a highly significant difference across the PTA severity categories (Table 5.7-1).

*Table 5.7-1: Difference in functional outcome according to PTA severity group*

| Kruksal Wallis Test | Chi-Square | df | 2 tailed Sig. |
|---|---|---|---|
| Barthel | 12.01 | 3 | .007 |
| OPCS - OSS | 16.26 | 3 | .001 |
| FIM+FAM Physical Function | 19.95 | 3 | <0.001 |
| FIM+FAM Psychological Function | 28.84 | 3 | <0.001 |
| ERSS | 23.24 | 3 | <0.001 |
| GOS | 12.27 | 3 | .007 |

There was a trend for functional deficit to increase with increasing severity on PTA. (Table 5.7-2 ).

*Table 5.7-2: Descriptive statistics of functional status by PTA*

| | | | | | | Percentiles | |
|---|---|---|---|---|---|---|---|
| | PTA Severity Category | N | Median | Min | Max | 25 | 75 |
| Barthel | Moderate - 1 to 24hours | 9 | 20 | 15.00 | 20.00 | 18.50 | 20.00 |
| | Severe - 1 to 7 days | 10 | 19 | 7.00 | 20.00 | 16.50 | 20.00 |
| | Very Severe -1 to 4 weeks | 41 | 20 | 10.00 | 20.00 | 20.00 | 20.00 |
| | Very Severe >4weeks | 28 | 19 | 3.00 | 20.00 | 17.00 | 20.00 |
| OPCS OSS | Moderate - 1 to 24hours | 9 | 4.25 | .00 | 13.65 | 1.25 | 8.32 |
| | Severe - 1 to 7 days | 10 | 5.38 | .50 | 18.30 | 1.78 | 10.58 |
| | Very Severe -1 to 4 weeks | 41 | 5.10 | .00 | 16.60 | 1.88 | 7.73 |
| | Very Severe >4weeks | 28 | 9.98 | .00 | 19.05 | 6.85 | 11.89 |
| FIM+FAM Physical Function | Moderate - 1 to 24hours | 9 | 109.00 | 92.00 | 112.00 | 99.50 | 110.50 |
| | Severe - 1 to 7 days | 10 | 106.00 | 48.00 | 112.00 | 88.25 | 111.00 |
| | Very Severe -1 to 4 weeks | 41 | 111.00 | 56.00 | 112.00 | 107.50 | 112.00 |
| | Very Severe >4weeks | 28 | 103.00 | 34.00 | 112.00 | 92.50 | 108.00 |
| FIM+FAM Psychological Function | Moderate - 1 to 24hours | 9 | 91.00 | 73.00 | 97.00 | 81.50 | 93.00 |
| | Severe - 1 to 7 days | 10 | 90.50 | 67.00 | 97.00 | 81.00 | 93.75 |
| | Very Severe -1 to 4 weeks | 41 | 84.00 | 62.00 | 98.00 | 77.50 | 90.50 |
| | Very Severe >4weeks | 28 | 71.50 | 35.00 | 96.00 | 63.25 | 77.75 |
| ERSS | Moderate - 1 to 24hours | 9 | 10 | 6.00 | 17.00 | 7.00 | 12.50 |
| | Severe - 1 to 7 days | 10 | 10 | 5.00 | 22.00 | 7.25 | 16.50 |
| | Very Severe -1 to 4 weeks | 41 | 9 | 3.00 | 18.00 | 6.50 | 12.50 |
| | Very Severe >4weeks | 28 | 15 | 8.00 | 25.00 | 12.00 | 16.75 |
| GOS | Moderate - 1 to 24hours | 9 | 4 | 3.00 | 5.00 | 3.00 | 4.50 |
| | Severe - 1 to 7 days | 10 | 4 | 3.00 | 5.00 | 3.00 | 4.25 |
| | Very Severe -1 to 4 weeks | 41 | 4 | 3.00 | 5.00 | 3.00 | 4.00 |
| | Very Severe >4weeks | 28 | 3 | 3.00 | 4.00 | 3.00 | 3.00 |

However, the group with a PTA of '1 to 7 days' appeared to function at a lower level than those with a PTA of '1 to 4 weeks' in all measures except for FIM+FAM Psychological Functioning. This apparent difference may be misleading given the smaller size of the '1 to 7 day' group and the wider interquartile ranges for that group as shown in (Table 5.7-2). As a result, cases that might be considered as outliers will have a disproportionate effect on group statistics. A Mann-Whitney U test showed the mean ranks for '1 to 7 day' PTA group are only significantly higher on Barthel (U=115.0, p = 0.005) and for Physical function on the FIM+FAM (U=110.5, p = 0.022). This possible anomaly was further examined by looking at the relationship of severity on PTA to functional outcome in each of the two diagnostic groups (Table 5.7-3).

*Table 5.7-3: Spearman's rho of PTA severity category to functional outcome by injury*

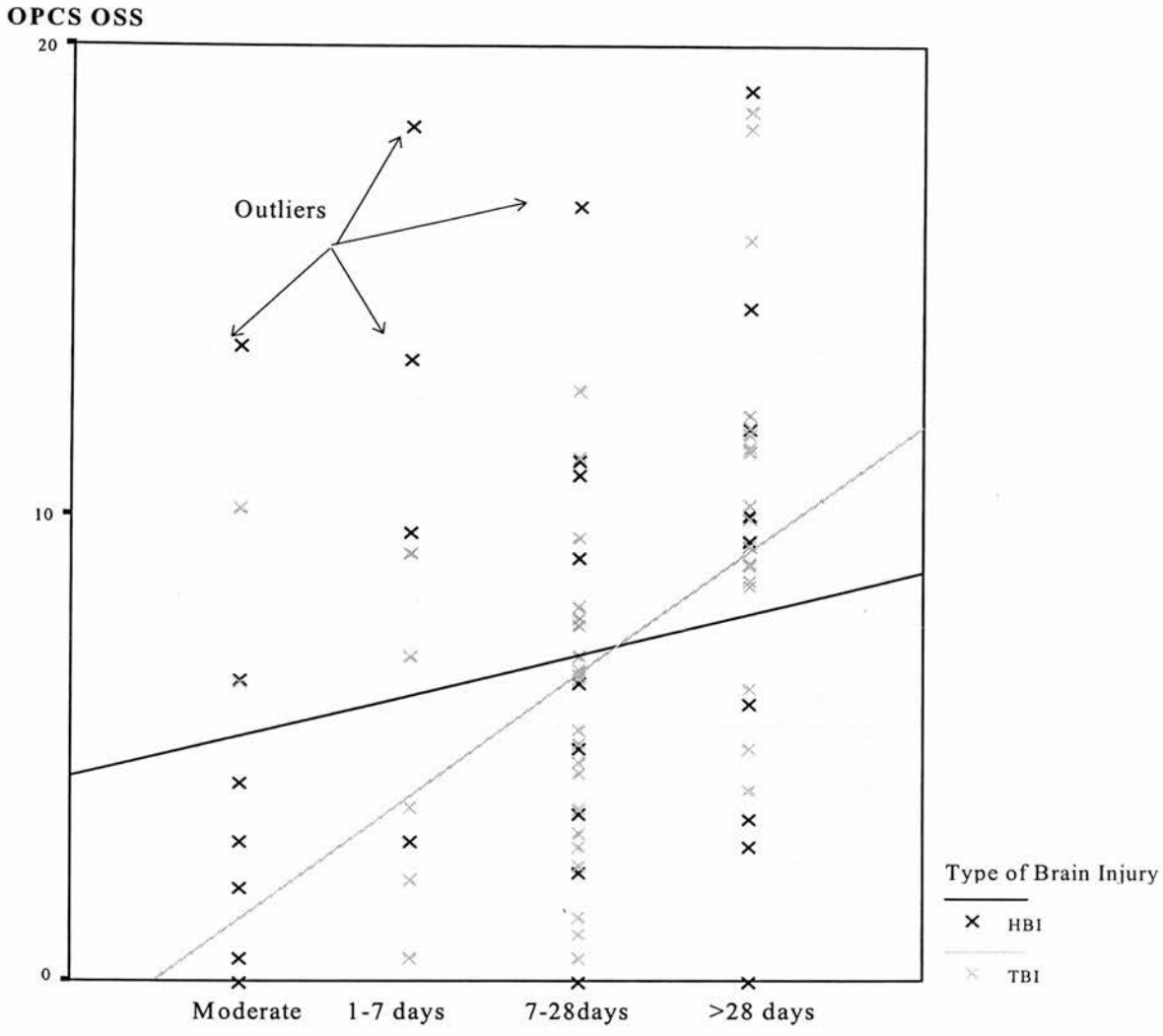
| | | Barthel | OPCS OSS | FIM+FAM Physical Function | FIM+FAM Psychological Function | ERSS | GOS |
|---|---|---|---|---|---|---|---|
| TBI (n=54) | PTA Severity | -.21 | .54** | -.41** | -.66** | .56** | -.55** |
| HBI (n=34) | PTA Severity | -.16 | .16 | -.01 | -.39* | .25 | -.15 |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Post Traumatic Amnesia severity was strongly related to functional outcome in all measures but the Barthel Index for the TBI group. However, in the HBI group, PTA severity only relates to the Psychological Function component of the FIM+FAM. This is further explored by looking at a scatterplot of the OPCS OSS scores in relation to PTA severity group (Figure 5.7-1). This shows that there are four cases who have high levels of disability despite being classified as having had a less severe injury using PTA. Each of these cases had a haemorrhagic rather than traumatic brain injury.

*Figure 5.7-1:Relationship of OPCS OSS and PTA severity by type of injury*




If the data is analysed excluding the four outlying HBI patients shown in Figure 5.7-1, there is a stronger correlation between PTA severity and a broader range of functional activities in the HBI group.

*Table 5.7-4: Relationship of PTA to functional outcome in HBI excluding outliers*

| | Spearman's rho | Barthel | OPCS OSS | FIM+FAM Physical Function | FIM+FAM Psychological Function | ERSS | GOS |
|---|---|---|---|---|---|---|---|
| HBI (n=30) | PTA Severity | -.41* | .35 | -.19 | -.53** | .47** | -.25 |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

The relationship between severity according to the WFNS category and functional outcome was also examined for the HBI group. This showed a similar level of correlation as PTA.

The relationship between severity and functional outcome was strongest when using PTA severity categories, and even then was most significantly related to functioning for the TBI group.

## 5.8 Difference between functional status at discharge and six weeks

In addition to evaluating the range and extent of disabilities at set time points following in-patient rehabilitation, the hypothesis that levels of function would be maintained after discharge has been proposed (Section 4.2). The main disability measure used to investigate this, was the FIM+FAM and comparisons between these scores at discharge from hospital and about six weeks later form the basis of the following finding.

### 5.8.1 Change in FIM+FAM Score

#### 5.8.1(i) FIM+FAM Total Score

In 56 (63%) of the 89 patients, the total FIM+FAM scores were either the same or better at six weeks after discharge than at the time of discharge, with a strong correlation between the two figures (Spearman rho=0.94). As deterioration in one item of the FIM+FAM in a particular patient could be counteracted by improvement in another resulting in the total score remaining the same, it is necessary to look at changes in individual items for each patient

#### 5.8.1(ii) FIM+FAM Items

All of the FIM+FAM scores on discharge correlated significantly with the six week follow up scores although some coefficients were quite low, for example dressing upper (Spearman rho=0.4). These lower coefficients indicate that change has occurred and Table 5.81 summarises the number of instances where there was no change, improvement or deterioration for each FIM+FAM item.

*Table 5.8-1: Change in FIM+FAM scores from discharge to six weeks follow-up (n=89)*

| Dimension | No Change | Improved | Deteriorated |
|---|---|---|---|
| Swallow | 80 | 7 | 2 |
| Feed | 76 | 8 | 5 |
| Grooming | 81 | 6 | 2 |
| Bathing | 81 | 5 | 3 |
| Dressing Upper | 62 | 9 | 18 |
| Dressing Lower | 61 | 12 | 16 |
| Toileting | 82 | 3 | 4 |
| Bladder | 73 | 10 | 6 |
| Bowel | 79 | 8 | 2 |
| Bed Transfers | 75 | 10 | 4 |
| Toilet Transfers | 71 | 15 | 3 |
| Bath Transfers | 59 | 16 | 14 |
| Car Transfers | 86 | 1 | 2 |
| Walk/Wheel | 74 | 9 | 6 |
| Stairs | 63 | 17 | 9 |
| Community Mobility | 79 | 8 | 2 |

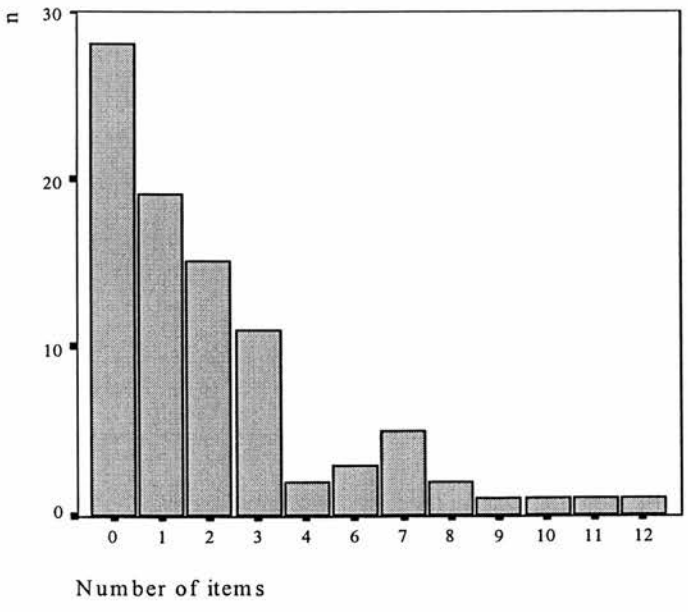
**(Table 5.8-1 continued)**

| | | | |
|---|---|---|---|
| Comprehension | 64 | 17 | 8 |
| Expression | 74 | 9 | 6 |
| Reading | 68 | 14 | 7 |
| Writing | 70 | 17 | 2 |
| Speech Intelligibility | 78 | 3 | 8 |
| Social Interaction | 66 | 15 | 8 |
| Emotion | 69 | 11 | 9 |
| Adjustment | 72 | 4 | 13 |
| Employability | 72 | 11 | 6 |
| Problem Solving | 67 | 14 | 8 |
| Memory | 67 | 14 | 8 |
| Orientation | 70 | 11 | 8 |
| Attention | 64 | 16 | 9 |
| Safety Judgement | 75 | 11 | 3 |

For any single item, the majority of subjects have maintained or improved their level of function. Twenty-eight (32%) subjects had maintained or improved their functional level across the range of FIM+FAM items, with 71 (80 % ) of the sample improving on at least one item.

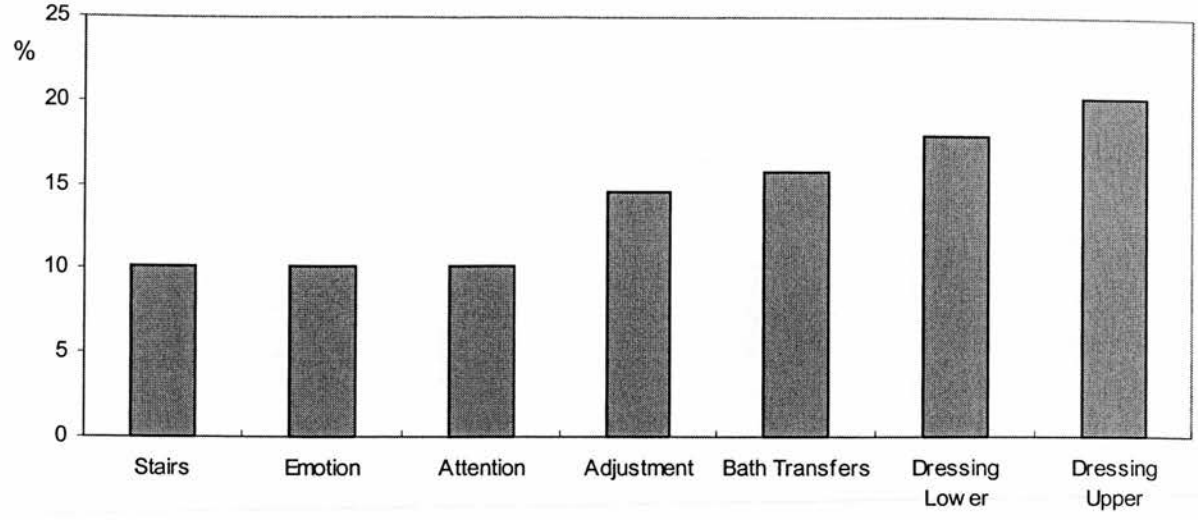
However, 61 people (68%) deteriorated in one or more items on the FIM+FAM (Figure 5.8-1). The median number of items showing deterioration was one per patient (range 0-12, IQR 1-3).

*Figure 5.8-1: Number of items showing deterioration on FIM+FAM for each patient (n=89)*




There were seven items for which 10% or more of the total study group had lower scores at the six week review than at discharge as summarised in Figure 5.8.2. This is expressed as a percentage of the total study group (n=89).

*Figure 5.8-2: Items on the FIM+FAM most frequently showing deterioration*




## 5.8.2 Factors involved in deterioration in the first six weeks

As this reduction in functional level following discharge was not predicted, aspects that may be linked to this reduction were examined. This is approached in three ways. The first is to explore whether there is any relationship between certain characteristics of the study population, and the total number of FIM+FAM items showing deterioration. Secondly, such characteristics were explored in relation to whether or not deterioration had occurred. Finally , the issue of items with scores of '5' or less, indicating reliance on others is considered.

### 5.8.2(i) Number of FIM+FAM items

The relationship between age, severity of injury indicators and length of acute hospital stay and the total number of items where deterioration occurred is summarised in Table 5.8-2.

*Table 5.8-2: Relationship between deterioration in functional level, age and severity*

| | Spearman rho | Sig. (2-tailed) | N |
|---|---|---|---|
| Age | .26* | .013 | 89 |
| Severity on PTA | .11 | .317 | 88 |
| Severity on GCS | -.04 | .716 | 82 |
| Acute Hospital LOS | .20 | .055 | 89 |

*. Correlation is significant at the .05 level (2-tailed).

There is a positive correlation between the number of items where deterioration occurred and increasing age. The correlation with length of acute hospital stay falls just below statistical significance and there is no correlation with severity of injury.

When the impact of age on the level of deterioration is further considered (Table 5.8-3), there is no difference between those in whom deterioration occurred and those in which a single item showed deterioration. Thereafter, there was a trend for the number of items to increase with age.

*Table 5.8-3: Extent of deterioration and age*

| Number of Items | N | Mean Age |
|---|---|---|
| 0 | 28 | 39.64 |
| 1 | 19 | 39.89 |
| 2-4 | 28 | 44.71 |
| 5 or more | 14 | 56.14 |

There was no significant difference in the number of items showing deterioration according to the type of injury.

Other factors considered were the length of stay in the rehabilitation unit and the overall level of disability as reflected in the total FIM and FIM+FAM score at discharge. The relationship between these characteristics of the study population and the number of FIM+FAM items showing deterioration is shown in Table 5.8-4.

*Table 5.8-4: Relationship between deterioration in functional level and discharge functional level*

| Spearman's rho | Number of Items |
|---|---|
| FIM+FAM Total | -.42** |
| FIM Total | -.41** |
| Rehabilitation LOS | .28** |

**. Correlation is significant at the .01 level (2-tailed).

The disability measures and the length of in-patient rehabilitation stay, related in a significant way to the number of items showing deterioration. The negative correlation for both the FIM+FAM and the FIM alone, indicate that the lower the total score at discharge (or greater functional deficit), the more items show deterioration.

In order to explore whether certain subscales of the FIM+FAM were more significantly related to the number of items showing deterioration, the subscale scores were considered separately (Table 5.8-5). All subscale scores, other than continence, are significantly associated with the number of items showing deterioration.

*Table 5.8-5: Relationship between discharge FIM+FAM subscale scores and deterioration.*

| | Spearman's rho |
|---|---|
| ADL | -.27** |
| Continence | -.19 |
| Transfers | -.38** |
| Locomotion | -.39** |
| Communication | -.24* |
| Psychosocial | -.36** |
| Cognition | -.35** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

It was suggested earlier (Section 5.2, Table 5.5-9), that factor analysis supported grouping the FIM+FAM items into two separate factors, Physical Functioning and Psychological Functioning. The relationship between these two factors and the number of items of deterioration is examined in Table 5.8-6 and shows similar correlation coefficients for both factors.

*Table 5.8-6: Relationship between deterioration and the two factors of the FIM+FAM*

| Spearman's rho | Physical Function | Psychological Function | FIM+FAM Total |
|---|---|---|---|
| Number of Items | -.40** | -.34** | -.42** |
| Physical Function | | .58** | .80** |
| Psychological Function | .58** | | .94** |

**. Correlation is significant at the .01 level (2-tailed).

This section has illustrated increasing age, greater functional deficit at discharge and length of stay in the rehabilitation unit correlated with the total number of FIM+FAM items deteriorating in the six weeks after discharge. However, these relationships account for only small amounts of the variance in the number of items of deterioration.

### 5.8.2(ii) Presence or absence of deterioration

The second approach of this exploration of deterioration, is to explore 'deterioration' versus 'no deterioration' in functional state after discharge. As mentioned above, 28 people maintained or improved function in each item whilst 61 people demonstrated lower scores in at least one FIM+FAM item.

As 'deterioration' is a dichotomous variable (the patient is either a member of the group who deteriorated or of the group who did not), logistic regression is an appropriate way to explore factors that might be predictive. Whilst there are restrictions to the amount of information one can gain from multivariate analysis in view of the sample size and the heterogeneous nature of the sample, this exploration may allow further identification of the relative importance of variables in the maintenance of functional level.

One way of interpreting logistic regression is to plot the two groups against the predicted probability of membership. If a model successfully predicts the two groups in this situation, those in the deteriorated

group will have predicted probability values further to the right of an equal probability at 0.5, and the non-members further to the left. The more separate the two series, on either side of equal probability at 0.5, the more accurate the prediction.

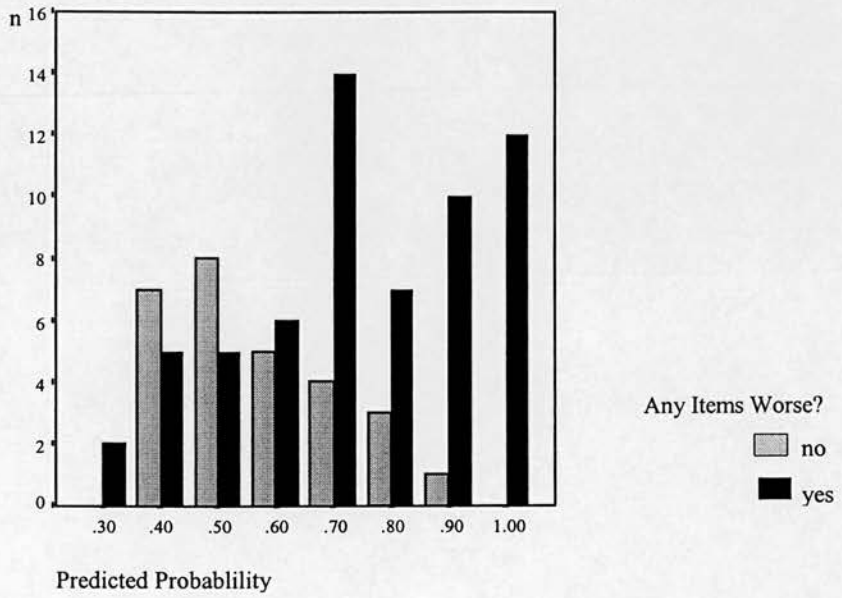
Earlier in this section, a number of variables which might be predictive of a reduction in functional status after discharge have been highlighted. The first logistic regression model therefore includes age and the discharge disability level on the two functional areas on the FIM+FAM (Table 5.8-7).

*Table 5.8-7: Logistic regression of deterioration by age and discharge functional deficit*

| Variable | B | S.E. | Wald | df | Sig | R | Exp(B) |
|---|---|---|---|---|---|---|---|
| Physical Function | -.109 | .056 | 3.731 | 1 | .053 | -.125 | .897 |
| Psychological Function | -.050 | .031 | 2.104 | 1 | .147 | -.031 | .956 |
| Age | .0180 | .014 | 1.635 | 1 | .201 | .000 | 1.018 |
| Constant | 15.189 | 5.659 | 7.204 | 1 | .007 | | |

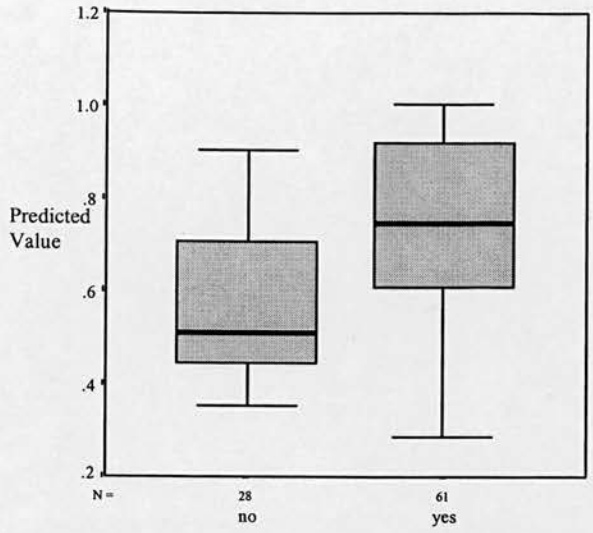
This information may be more easily seen in Figure 5.8-3, a bar chart of the predicted probability of group membership with the dark bars representing those who have deteriorated since discharge.

*Figure 5.8-3: Predicted probability of deterioration using FIM+FAM and age*



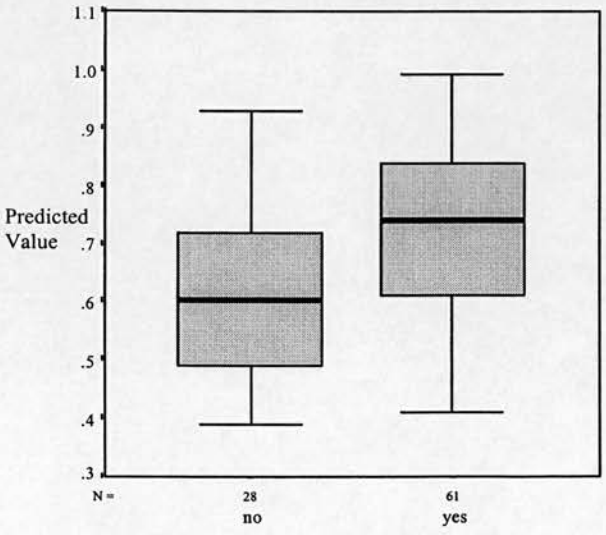

Although there is a trend for those who have 'deteriorated' to be further to the right of the predicted values than those in the 'not deteriorated' group, there is a fair degree of crossover. In addition, few values are below 0.5 predicted probability. However, Figure 5.8-5 indicates that despite the inadequate fit of the model, the mean values of predicted probability are on either side of 0.5, and therefore further investigation of predictors may be valuable.

*Figure 5.8-4: Predicted probability of deterioration FIM+FAM and age*




A stepwise procedure of the same variables includes only Psychological Functioning from the FIM+FAM as it was the only variable in the model with a significance value of less than 0.05. Although there is slight improvement in the model's ability to predict membership of the deteriorated group, the model is less accurate on prediction of the group who do not have any worse items as shown when comparing the previous figure with Figure 5.8-5.

*Figure 5.8-5: Predicted probability of deterioration using FIM+FAM Psychological Function*




Choosing variables to enter into this sort of analysis is a pragmatic rather than purely scientific matter and it may be that a more successful model could be formed by including other factors. For that reason, variables have been included that reflect a range of areas suggested to impact on outcome as discussed in Chapter 3.

Firstly, premorbid characteristics such as sex, social class, years of education and age have been considered. Secondly, injury details such as type of injury (TBI or HBI), the side of the brain injured and severity in terms of GCS and PTA have been included. In addition, acute hospital length of stay has been included as an indicator of the severity of complications and finally, variables reflecting functional level on discharge have been included.

Of all the variables, a step wise procedure again only includes FIM+FAM Psychological Function to produce the predicted probability values. Never the less, it is appropriate to consider the individual significance values of the other variables in case entering them into the equation may produce a more accurate model for this sample.

Prior to entry of any variables, those aspects most related to membership of the deteriorated group are shown in Table 5.8-8.

*Table 5.8-8: Variables most strongly contributing to deterioration in one FIM+FAM item*

| Variable | Score | df | Sig | R |
|---|---|---|---|---|
| FIM+FAM 1 | 7.75 | 1 | .005 | .23 |
| FIM+FAM 2 | 8.86 | 1 | .003 | .25 |
| Rehab LOS | 5.58 | 1 | .018 | .18 |
| Acute LOS | 3.30 | 1 | .069 | .11 |

Table 5.8-9 shows the significance of each variable once FIM+FAM Psychological dimensions has been entered.

*Table 5.8-9: Variables excluded on stepwise logistic regression*

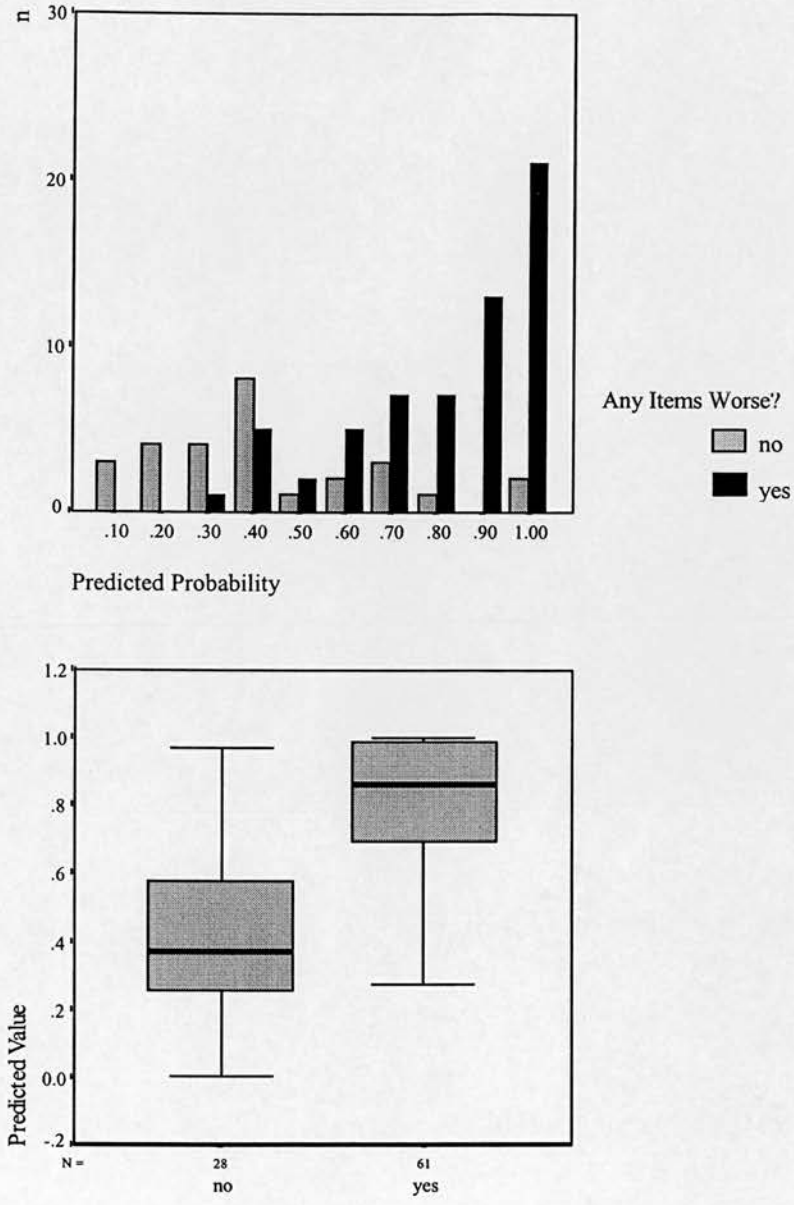
| Variable | Score | df | Sig | R |
|---|---|---|---|---|
| Physical Function | 7.83 | 1 | .05 | .13 |
| Sex | 3.34 | 1 | .07 | .11 |
| Age | 2.71 | 1 | .10 | .08 |
| PTA Severity | 2.56 | 1 | .11 | .07 |
| Years of Education | 1.77 | 1 | .18 | .00 |
| Rehab LOS | 1.74 | 1 | .19 | .00 |
| Acute LOS | 0.43 | 1 | .51 | .00 |
| Type of Injury | 0.41 | 1 | .52 | .00 |
| Side of injury | 0.08 | 1 | .78 | .00 |
| Social Class | 0.01 | 1 | .98 | .00 |

It can be seen that the effect of variables such as FIM+FAM Physical Functioning and acute and rehabilitation LOS, are removed as they are covariants of Psychological Function on the FIM+FAM.

In an attempt to explore whether the inclusion of variables with smaller, albeit non-significant p values would be any more successful in prediction of deterioration, a straightforward 'enter' model will be used

with Physical and Psychological Function at discharge, Sex, Age, PTA severity, and Years of education (Figure 5.8-6).

*Figure 5.8-6: Predicted probability of deterioration using complex model*




This model brings about a better separation of those who deteriorate and those who do not, as can be seen in the above figures. However, the analysis highlights that even with the inclusion of a wide range of variables, prediction of this degree of deterioration is complex.

It may be that dividing the group at the level of those who deteriorate by up to one item from those who deteriorate by two or more items may give further insight into predictors. The rationale behind this division, is that there were almost even numbers in each group as shown in Table 5.8-3. Further, on a

pragmatic level, it may be that this division allows for some variability in the reliability of the scale whilst still allowing a predictive model.

### 5.8.2(iii) Presence or absence of two or more items of deterioration

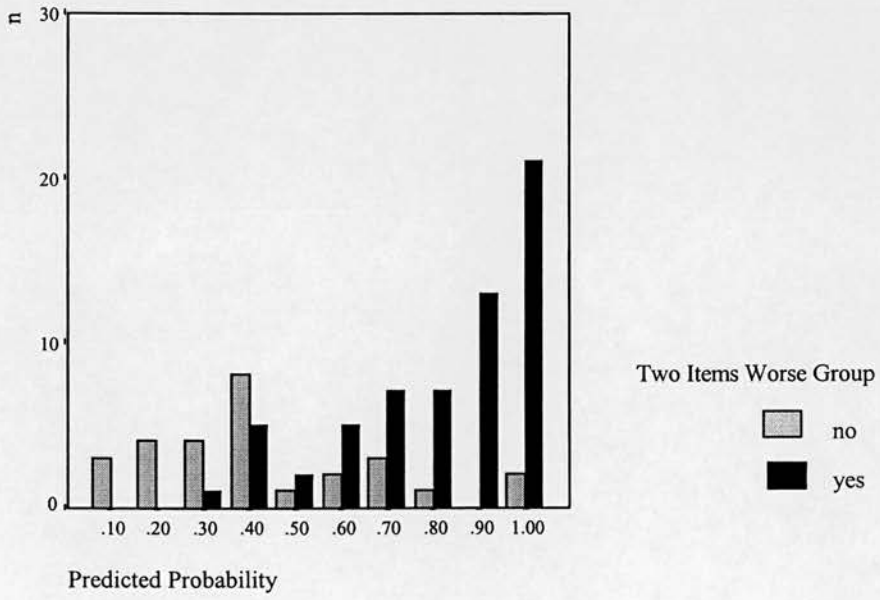
Again logistic regression has been used to explore whether trends seen in the previous section are found to be predictive of greater degree of deterioration in functional status after discharge from in-patient rehabilitation (Table 5.8-10).

*Table 5.8-10: Predicted probability of two item worse group with FIM+FAM factors and age*

| Variable | B | S.E. | Wald | df | Sig | R | Exp(B) |
|---|---|---|---|---|---|---|---|
| Physical Function | -0.003 | 0.023 | 0.016 | 1 | 0.901 | 0.000 | 0.997 |
| Psychological Function | -0.052 | 0.026 | 4.103 | 1 | 0.043 | -0.131 | 0 .949 |
| Age | 0.029 | 0.013 | 5.050 | 1 | 0.025 | 0.158 | 1.029 |
| Constant | 3.072 | 2.238 | 1.883 | 1 | 0.170 | | |

Both FIM+FAM Psychological Function and age have again significantly contributed to this model with Physical Function not involved to a significant degree. A bar chart is shown to aid interpretation (Figure 5.8-7).

*Figure 5.8-7: Predicted deterioration in two or more items using FIM+FAM and age*




The model has predicted membership of the 'two item worse group' better than the earlier model of 'one item worse' when using age and functional performance at discharge. This is indicated by a better separation of predicted probabilities on either side of 0.5. However, as shown in Table 5.8-10, there is a marked degree of error in the predictive model. In contrast to the 'one item versus none worse' analysis, there is almost no improvement in the model by including other variables. A model using FIM+FAM Psychological Function and Age has been the best predictor of this level of deterioration from a wide range of variables.

### 5.8.2(iv) Extent of deterioration

The score of '5' or less on the FIM+FAM indicates the need for help or supervision of another person. Therefore a further approach is to determine whether there was a change in the numbers scoring '5 or less' at six week follow up. The median number of items rated 5 or less at review was six .

Of the 89 subjects: 39 (44%) had fewer items scoring '5 or less' suggestive of improvement in functional status; 25 (28%) scored '5 or less' on more items and in 25 (28%), there was no change at six week follow up. Those variables which contributed to group membership in the previous levels of deterioration do not distinguish these groups with all predicted probabilities being less than 0.5.

The analysis in this section has indicated that sensitivity of prediction (adequately predicting those who will deteriorate) is at the cost of specificity (incorrectly predicting those who will not deteriorate) and requires a complex model incorporating a combination of premorbid factors, severity indicators and functional measures. However the most influential factors involved in deterioration on the FIM+FAM were increased age at injury and increased functional deficit, particularly in Psychological Function on the FIM+FAM at discharge.

## 5.9 Other results of the six week assessment

### 5.9.1 Services involved at six weeks after discharge

As part of the semistructured interview, information was obtained regarding the involvement of other professionals in the weeks since discharge. All but two people had been seen by at least one member of health care or social services staff. Most people (n=80, 90%) had seen their GP since discharge but 17 of these (21%), had contact with no other professional. Sixteen percent (n=14) of the sample were being attended by five or more separate professions including their GP. Further details are shown below (Table 5.9-1).

*Table 5.9-1: Services involved at six weeks*

| n=89 | Referred - Seen No Action | Referred - Not seen Action* | Not Referred - Action* |
|---|---|---|---|
| Home Help | 11 | 1 | 3 |
| District Nurse | 10 | 1 | 1 |
| Health Visitor | 2 | 2 | |
| General Practitioner | 80 | | |
| Physiotherapist | 40 | 3 | 5 |
| Occupational Therapist | 37 | 6 | 5 |
| Speech & Language | 9 | 5 | 2 |
| Psychologist | 20 | 5 | 3 |
| Day Hospital | 10 | | 1 |
| Local Authority Day Centre | 5 | | 2 |
| Training Centre / College | 3 | 1 | |
| Voluntary Organisation | 3 | 5 | 18 |
| Social Worker | 17 | 3 | 2 |

*. Action = Liaison with or referral to the service

The shaded columns highlight where action to contact a service was required by the researcher as a result of the assessment. In 21 cases, referrals made prior to discharge had not been followed through as planned. Contact was most frequently required for only one therapy or service, but in seven cases it was in connection with two or more services.

The other reason for contacting services, was where assessment at six weeks indicated that a new referral may be appropriate (n=28). For 18 people, this was in response to a request from the patient and/or their carer for information about the local Headway or another voluntary organisation for people with brain injury in their area. In five of these 18 cases, a new referral was also required with other formal health or social services. In a number of cases where the patient was already being seen, liaison with the treating therapist was required to confirm information, or to pass on concerns that the patient or relative had expressed during the visit. Such contact was most frequently made with occupational therapists in connection with 15 people (41% of those attending one), and psychology

for 10 people (50% of those attending a psychologist). Having obtained permission from the patient and where relevant the carer, the consultant in charge of the patient's medical management was provided with those details of the assessment that the researcher thought might be useful. Referral for a repeat, or early attendance at the consultant's clinic was sought in two cases. In five cases, the researcher sought advice from the consultant regarding the patient's medical treatment to ensure advice given at the visit was appropriate.

### 5.9.2 Carer perspective at six weeks after discharge

Of the 89 subjects, 82 were seen with the person identified by them as their main support. In the remaining cases, the patient could not identify anyone who fulfilled this role. The majority of carers were spouses n=40 (49%) or parents 27 (33%) (Table 5.9-2).

*Table 5.9-2: Relationship of carer*

| (n=82) | Frequency | Percent |
|---|---|---|
| Husband | 14 | 17 |
| Wife | 26 | 32 |
| Parent | 27 | 33 |
| Sibling | 6 | 7 |
| Offspring | 6 | 7 |
| friend | 3 | 4 |

### 5.9.3 The Relative's Questionnaire

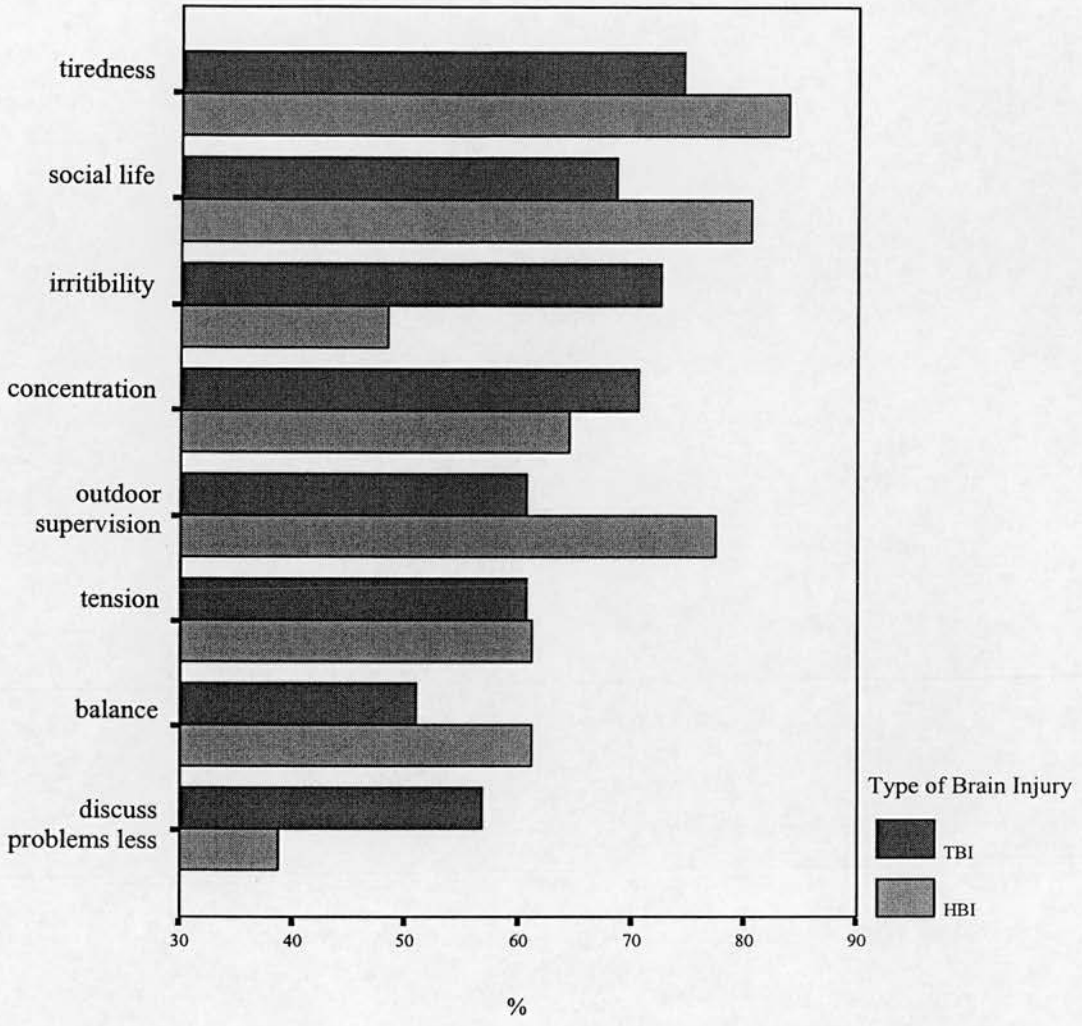
The Relative's Questionnaire (RQ) addresses the carer's view of difficulties experienced by the patient since their brain injury. The most frequently reported difficulties were subjective and physical symptoms. In two areas there were significantly more items reported in the TBI (n=51) group than in the HBI (n=31) (Table 5.9-3).

*Table 5.9-3: Frequency of problems on RQ reported by carers*

| **RQ Dimension** | **No of Items** | **Number reporting difficulties** | **%** | **Difference between HBI and TBI Mann-Whitney U test** |
|---|---|---|---|---|
| Physical Symptoms | 10 items | 71 | 87 | |
| Subjective Symptoms | 7 items | 80 | 98 | |
| Emotional Disturbance | 7 items | 68 | 83 | 553.0, p=0.001 |
| Disturbed Behaviour | 6 items | 58 | 70 | |
| Language | 3 items | 48 | 59 | |
| Memory | 6 items | 67 | 82 | 692.5, p=0.032 |
| Dependency | 7 items | 67 | 82 | |
| Social Behaviour | 3 items | 68 | 83 | |

All but one carer identified problems on the 50 items which are scored, with the median number being 23 (IQR - 11 to 30). The eight most frequently reported problems are shown in Figure 5.9-1.

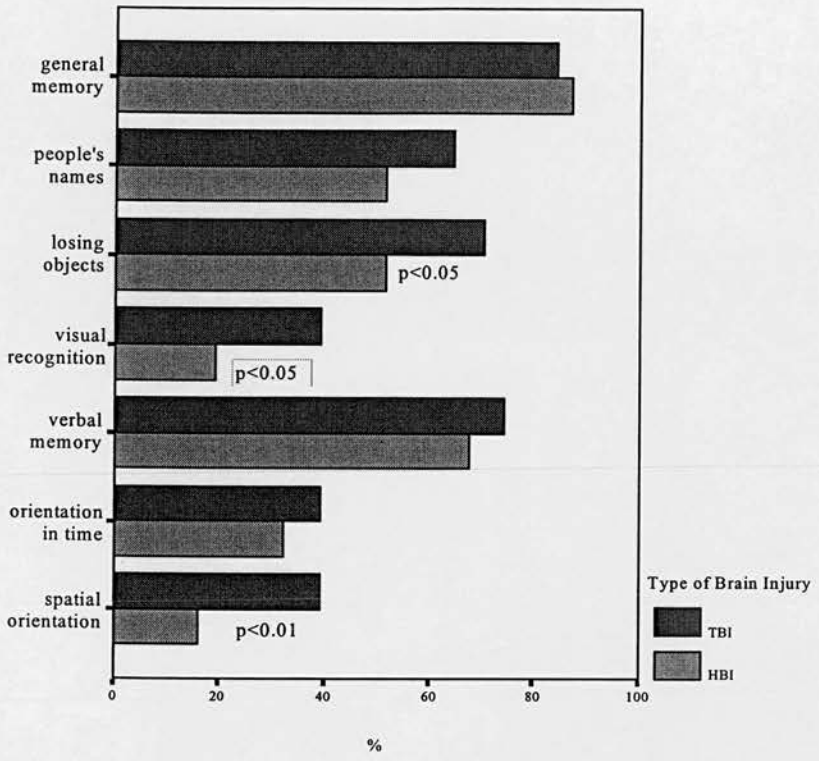
*Figure 5.9-1: Most frequently reported problems on RQ*




Similar proportions in each carer group reported that the patient had problems with tension/anxiety. There appeared to be a greater proportion of carers in the HBI group reporting that the patient had problems with tiredness, social life, increased need for supervision outdoors and balance problems. Further, a greater proportion of carers in the TBI group reported that they now discussed problems less and that the patient was more irritable. However, these apparent differences were only significant for 'irritability'($\chi^2$=4.31, p=0.04).

The Memory dimension in the RQ begins with the general question 'is the patient's memory worse than before' and is then followed by six specific memory difficulties which are scored. Whilst similar proportions of each diagnostic group reported changes in response to the initial general question, there was a significant difference between the number of TBI and HBI carers reporting specific memory problems as shown on Figure 5.9-2.

*Figure 5.9-2: Memory problems reported on RQ*




Spearman's rank correlation was used to explore the relationship between the number of items on the RQ reported as changed since the injury, severity of injury and functional deficit at six weeks (Table 5.9-4).

*Table 5.9-4: Correlation of number of items to functional deficit in TBI (n=50) and HBI (n=31)*

| Spearman's rho | PTA Severity | | OPCS OSS | | ERSS | |
|---|---|---|---|---|---|---|
| | TBI | HBI | TBI | HBI | TBI | HBI |
| Physical | .20 | -.03 | .51** | .48** | .56** | .48** |
| Subjective | .37** | .02 | .37** | .48** | .49** | .42* |
| Emotion | .43** | -.13 | .26 | .26 | .41** | .15 |
| Behaviour | .44** | .03 | .31* | .17 | .46** | .07 |
| Language | .49** | .28 | .40** | .58** | .51** | .43* |
| Memory | .42** | .24 | .59** | .55** | .61** | .42* |
| Dependency | .44** | .04 | .60** | .75** | .68** | .76** |
| Social Behaviour | .17 | .08 | .35* | .60** | .44** | .49** |
| Total | .47** | .03 | .53** | .67** | .64** | .56** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Injury severity did not relate significantly to any RQ dimensions in the HBI group but did to most for the TBI group. The ERSS score is related strongly to all dimensions on the RQ except for emotion

and behaviour for the HBI group. The weakest relationship for both groups on the OPCS OSS was to the RQ emotion and behaviour dimensions. However, the OPCS dimension specifically focussing on behaviour, relates more strongly, albeit still not significantly for the HBI group (Table 5.9-5).

*Table 5.9-5: Correlation of number of items to score on OPCS Behaviour dimension*

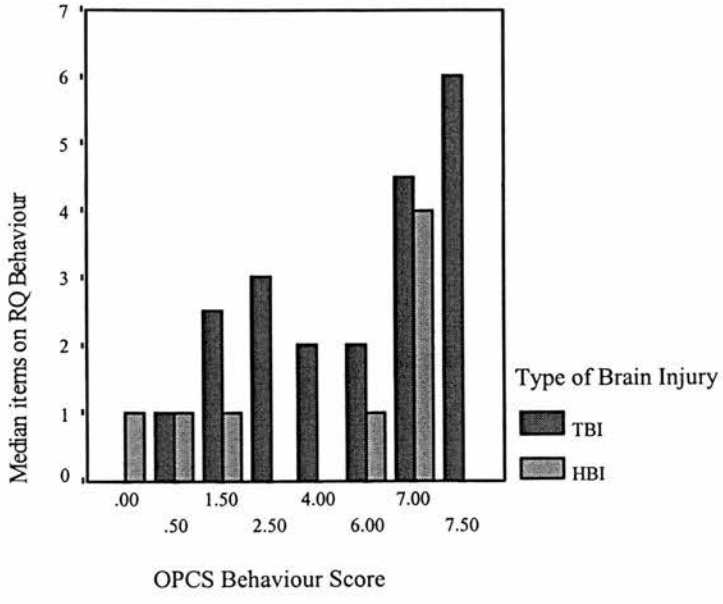
| | Behaviour | |
|---|---|---|
| Spearman's rho | TBI | HBI |
| Physical | .42** | .51** |
| Subjective | .40** | .53** |
| Emotion | .53** | .36* |
| Behaviour | .54** | .32 |
| Language | .47** | .44* |
| Memory | .54** | .27 |
| Dependency | .48** | .49** |
| Social Behaviour | .43** | .52** |
| Total | .60** | .59** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

This is further explored in Figure 5.9-3 where a trend for the number of RQ behaviour items and the OPCS behaviour score to increase in line with one another is demonstrated for the TBI group. However, it is only at higher scores on the OPCS that the number of items on the RQ rises for the HBI group.

*Figure 5.9-3: Behaviour score on RQ and OPCS by injury*



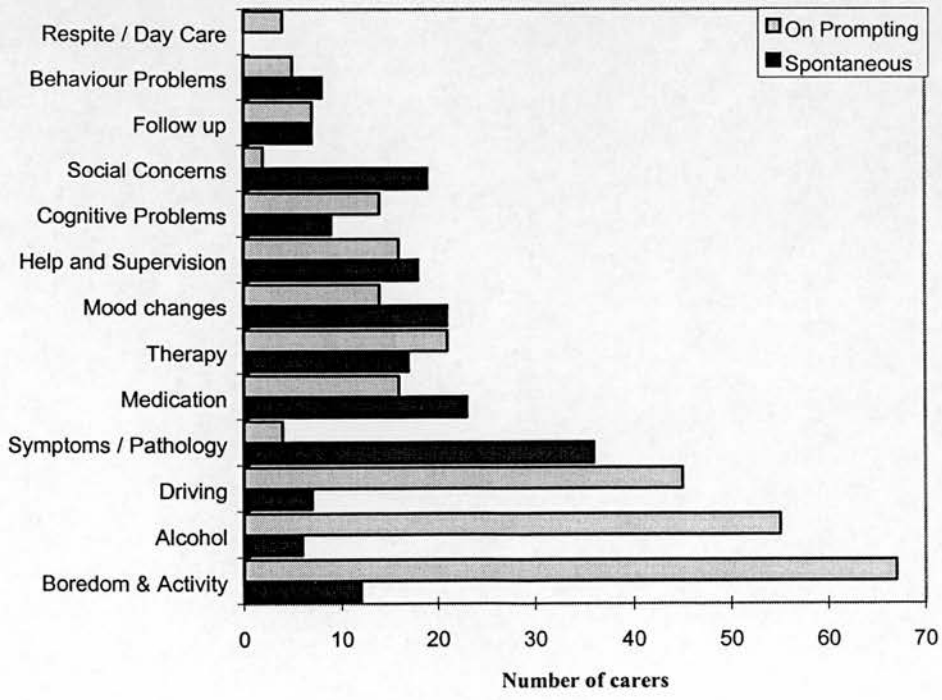
### 5.9.4 Information requested by carer

The semistructured interview also tried to determine areas where people considered that they required more information. The open question 'are there any areas you would like more information or help with?' was used to elicit 'spontaneous, undirected requests and 70 (85%) carers asked about at least one area of concern. When the prompt list was used, all but one carer identified particular areas on which they wanted more information. Most of the information requested may be categorised as follows (Table 5.9-6) and Figure 5.9-4 illustrates the number of requests in each area raised.

*Table 5.9-6: Areas where information was requested by carers*

| Information Area | Examples of Specific Items |
|---|---|
| **Physical symptoms** | pain, visual problems, tiredness, explanation of pathology |
| **Medication** | reasons for taking, dosage, side effects |
| **Changes in mood** | reasons for, and how to cope with low mood |
| **Social concerns** | housing, benefits, employment |
| **Help and supervision needs** | how best to help, safety concerns |
| **Therapy** | amount of therapy, how to incorporate at home |
| **Boredom and activities** | lack of structure to the day, only watching TV |
| **Dealing with cognitive problems** | how to deal with memory problems |
| **Dealing with behaviour problems** | how to react with angry outbursts |
| **Driving** | legal situation, car insurance |
| **Follow up appointments** | not reviewed by neurosurgical unit, transport difficulties |
| **Alcohol** | safe limits |
| **Respite / Day Care** | new need for respite |

*Figure 5.9-4: Information requested*



Information was most frequently sought spontaneously in areas concerning explanations of pathology, changes in mood and social concerns such as housing, benefits and work. A number of areas had few spontaneous requests for information, but on prompting seemed to be of interest to patients and their carers. This was particularly evident in concerns around alcohol consumption, driving, and other activities and dealing with boredom.

There was no significant difference in the number of areas where information was requested by the carers of individuals injured through trauma or haemorrhage. Further, there was no significant relationship between the initial injury severity and the amount of information requested by carers.

However, the type of information people requested was frequently related to the type and severity of disability. For example, information about dealing with cognitive problems was most frequently requested in households where the patient had significantly higher ranked levels of cognitive disability recorded on FIM+FAM Cognitive Function (Mann-Whitney $U=357.0$, $p=0.004$) and the OPCS Intellectual Function dimension (Mann-Whitney $U=362.5$, $p=0.004$). In other items such as alcohol use or activity levels, there was no relationship to disability type or level.

The majority of carers felt that although they now required information, there had been enough provided whilst in hospital. However, 14 (17%) expressed that they would have wished more information prior to discharge.

## 5.10 Profile of function at 15 months after discharge

Of the 89 people seen at six weeks after discharge, 79 (89%) were followed up 15 months after discharge from inpatient rehabilitation.

Of the ten people not seen, three had died, two refused follow-up visits, two could not be contacted and a further three were unavailable for the following reasons: one was in gaol for an offence committed prior to his injury, one was seriously ill in hospital following another HBI, and one was not available for assessment due to being away at university.

Fifty-six (70%) of the 79 patients had not required medical intervention other than attendance at a general practitioner or routine follow up in the intervening period. Five people had been referred to hospital for neurological problems such as the onset of seizures, and in case a further brain injury. Thirteen people had hospital treatment for non-neurological conditions and five had received specialist psychiatric services.

### 5.10.1 Total Scores

As at the six week assessment, the total scores correlated in a highly significant way (Table 5.10-1).

*Table 5.10-1: Spearman's rho for total scores*

| | Barthel | OPCS - OSS | FIM | FIM+ FAM | ERSS | GOS |
|---|---|---|---|---|---|---|
| Barthel | | -.66** | .69** | .66** | -.65** | .52** |
| OPCS - OSS | -.66** | | -.90** | -.89** | .87** | -.76** |
| FIM | .69** | -.90** | | .98** | -.92** | .83** |
| FIM+FAM | .66** | -.89** | .98** | | -.95** | .85** |
| ERSS | -.65** | .87** | -.92** | -.95** | | -.85** |
| GOS | .52** | -.76** | .83** | .85** | -.85** | |

**. Correlation is significant at the .01 level (2-tailed).

Further, the 15 month assessments correlated strongly with the corresponding measures at six weeks (Table 5.10-2).

*Table 5.10-2: Spearman's rho between total scores at six weeks and 15 months*

| | Barthel 15mths | OPCS OSS 15mths | FIM 15mths | FIM+FAM 15 mths | ERSS 15 mths | GOS 15mths |
|---|---|---|---|---|---|---|
| Barthel 6 wks | .68** | -.65** | .62** | .61** | -.60** | .49** |
| OPCS OSS 6 wks | -.54** | .79** | -.79** | -.79** | .72** | -.64** |
| FIM 6 wks | .60** | -.77** | .83** | .84** | -.77** | .72** |
| FIM+FAM 6 wks | .57** | -.76** | .82** | .85** | -.78** | .72** |
| ERSS 6 weeks | -.52** | .75** | -.77** | -.79** | .78** | -.70** |
| GOS 6 weeks | .38** | -.65** | .69** | .73** | -.72** | .74** |

**. Correlation is significant at the .01 level (2-tailed).

The proportion of patients at the ceiling level on each measure had increased with the lowest number being found on the FIM+FAM and ERSS (Figure 5.10-1).

*Figure 5.10-1: Number of patients at ceiling level on measures*

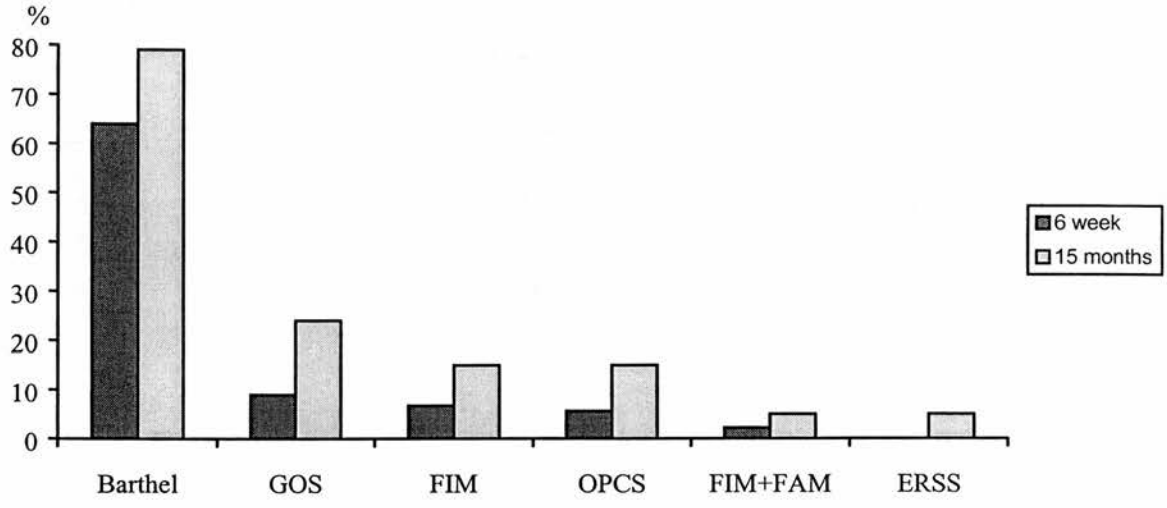



Figure 5.10-2 shows the percentage deficit scores for the 15 month assessment. The pattern is similar to the six week assessment (see figure 5.5-2) with a steep increase in the proportion of the population scoring at lower levels on the FIM, the FIM+FAM and Barthel, with a more gradual rise in the OPCS and ERSS.

*Figure 5.10-2: Scores for cumulative percentage of the group*

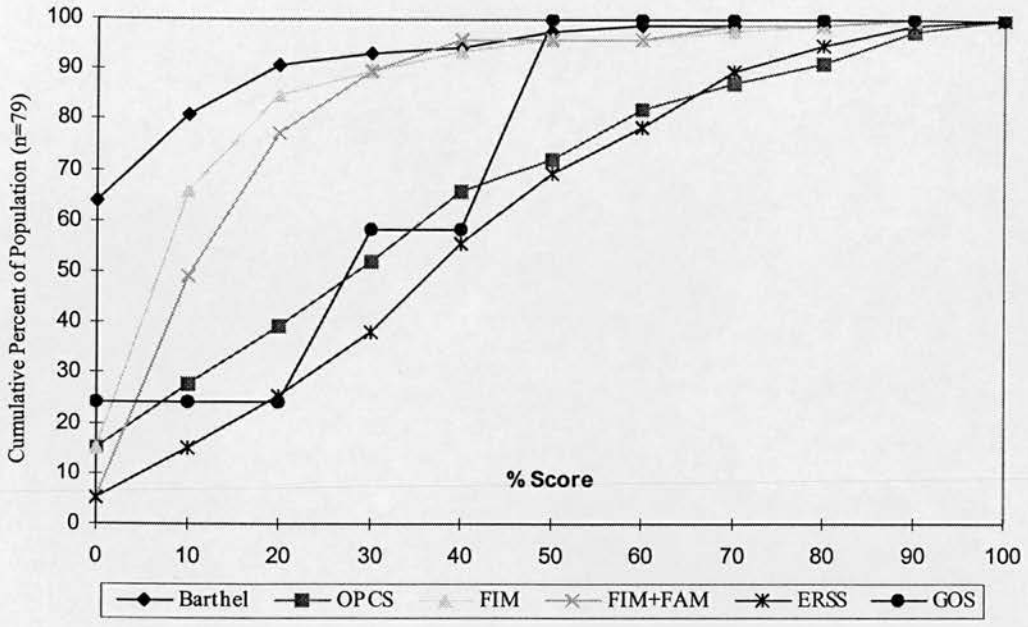
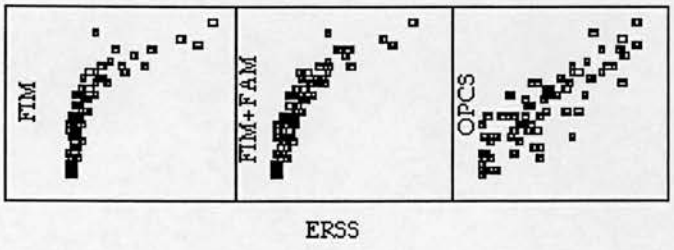



Figure 5.10-2 indicates a more linear relationship between the ERSS and the OPCS than with the other disability measures, whilst the correlation coefficients (Table 5.10-1) imply a closer relationship between the FIM, FIM+FAM and ERSS. In order to investigate this more fully, a scatterplot of the variables is shown below (Figure 5.10-3).

*Figure 5.10-3: Relationship between percentage disability scores and percentage ERSS score*




The scatterplot shows that the OPCS relates to the ERSS in a linear way, with a gradual increase in OPCS score along the range of ERSS scores. However, there is little change in disability on the FIM+FAM or FIM at lower levels of the ERSS and as levels increase, the relationship is curved rather than linear. As would be expected, the relationship of the FIM+FAM (and FIM) to the OPCS is also curvilinear. Using only the information from correlation coefficients in this case is misleading.

The type of injury has made no significant difference to the total scores at 15 months although on the Barthel, the difference almost reaches significance with the HBI group more dependent (Mann Whitney $U = 613.5$, $p=0.054$).

The following section evaluates the subscales on each measure, and where appropriate, the individual item scores. Emphasis is placed not only on the profile of disability at 15 months, but also on the change that has occurred over time.

## 5.10.2 Subscales and Item scores

### 5.10.2(i) The Barthel Index

The median scores for both the ADL and Mobility subscales of the Barthel were found to be at the ceiling level of the measure. However, in contrast to the six week assessment, there was a significant difference between the scores for the TBI and HBI group for mobility (Mann-Whitney U=558.5, p=0.003) with the HBI patients being more dependent. Few subjects had deteriorated on the Barthel ADL subscales (n=5) or in mobility (n=4) and the TBI group have proportionately fewer areas of deterioration and more improved ranks than the HBI group (Table 5.10-3).

*Table 5.10-3: Change in Barthel score for TBI and HBI Groups*

| | | Negative Differences (Worse Score) | Positive Differences (Improved Score) |
|---|---|---|---|
| TBI (n=47) | Mobility | 1 (2%) | 7 (15%) |
| | ADL | 2 (4%) | 12 (26%) |
| HBI (n=32) | Mobility | 3 (6%) | 3 (9%) |
| | ADL | 3 (9%) | 5 (16%) |

A sign test of the change in ranks, indicated that for the TBI group alone, the change is significant for both ADL (p=0.013) and Mobility (p=0.017) since the six week assessment. However, a Mann-Whitney U test showed that there was no significant difference in the extent of change between the two groups (ADL U=686.0, p=0.207; Mobility U=649.5, p=0.194).

### 5.10.2(ii) The FIM+FAM

The median FIM+FAM dimension scores were similar to those at the six week assessment for the group as a whole (Table 5.10-4).

*Table 5.10-4: FIM+FAM dimensions scores at 15 months*

| | | ADL | Continence | Transfers | Loco-motion | Commun-ication | Psycho-social | Cognition |
|---|---|---|---|---|---|---|---|---|
| | Best Possible | 49 | 14 | 28 | 21 | 35 | 28 | 35 |
| | Worst Possible | 7 | 2 | 4 | 3 | 5 | 4 | 5 |
| Mean | | 46.20 | 13.52 | 25.51 | 17.27 | 31.68 | 22.04 | 27.81 |
| Median | | 49.00 | 14.00 | 28.00 | 20.00 | 33.00 | 23.00 | 29.00 |
| Std. Deviation | | 6.40 | 1.76 | 4.98 | 4.89 | 3.75 | 4.79 | 6.51 |
| Percentiles | 25 | 47.00 | 14.00 | 26.00 | 15.00 | 30.00 | 19.00 | 24.00 |
| | 75 | 49.00 | 14.00 | 28.00 | 21.00 | 34.00 | 26.00 | 34.00 |

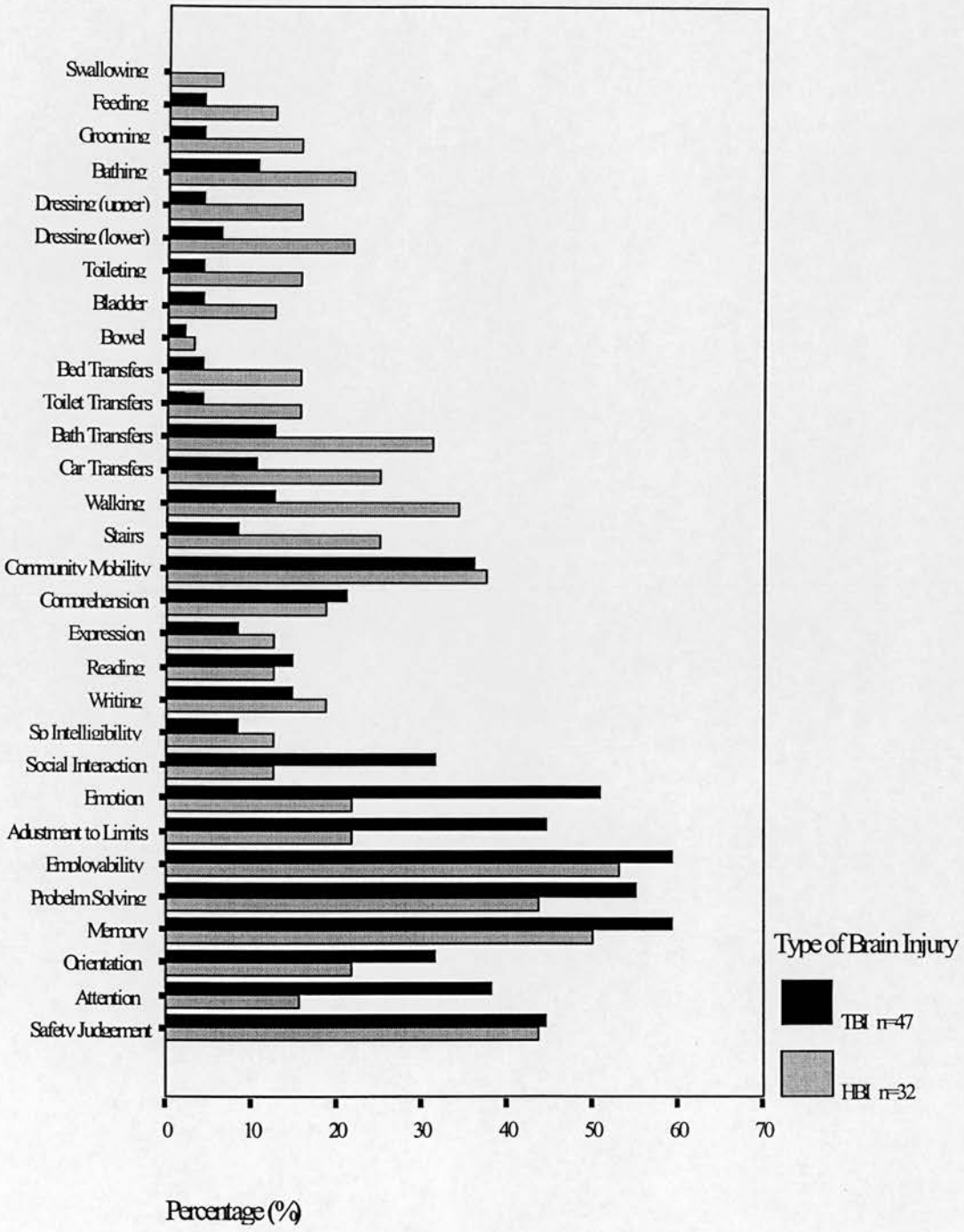
A difference was found between the TBI and HBI groups at 15 months, with the HBI group having significantly greater functional deficit in ADL and Transfers. There was a trend for the TBI group to be have lower ranked scores than the HBI in communication, social interaction and cognitive function although this difference was not significant (Table 5.10-5).

*Table 5.10-5: Difference between TBI and HBI on FIM+FAM at 15 month follow up*

| | **Type of Injury** | **Mean Rank** | **Sum of Ranks** | **Mann - Whitney U** | **p value** |
|---|---|---|---|---|---|
| ADL | TBI (n=47) | 44.17 | 2076.00 | | |
| | HBI (n=32) | 33.88 | 1084.00 | 556.0 | .019 |
| Continence | TBI | 41.22 | 1937.50 | | |
| | HBI | 38.20 | 1222.50 | 694.5 | .298 |
| Transfers | TBI | 44.33 | 2083.50 | | |
| | HBI | 33.64 | 1076.50 | 584.5 | .024 |
| Mobility | TBI | 43.63 | 2050.50 | | |
| | HBI | 34.67 | 1109.50 | 581.5 | .080 |
| Communication | TBI | 38.36 | 1803.00 | | |
| | HBI | 42.41 | 1357.00 | 687.0 | .454 |
| Psychosocial | TBI | 36.96 | 1737.00 | | |
| | HBI | 44.47 | 1423.00 | 609.0 | .151 |
| Cognitive | TBI | 37.52 | 1763.50 | | |
| | HBI | 43.64 | 1396.50 | 635.5 | .243 |

Over half the group required assistance from another person in the performance of day to day functions (Figure 5.10-4).

*Figure 5.10-4: Percentage requiring help on individual FIM+FAM items by type of injury at 15 months*




The difference between the two groups in numbers who required assistance was significant for walking ($\chi^2$=4.06, p=0.44) and emotion ($\chi^2$=5.63, p = 0.018).

Table 5.10-6 indicates where the scores on individual FIM+FAM item were significantly different between the TBI and HBI group. Given the multiple testing, one needs to be cautious about these results

but, the HBI group were significantly more disabled in ADL and Mobility items and the TBI group had lower scores (worse function) in items of psychosocial functioning.

*Table 5.10-6: Difference on FIM+FAM item scores between TBI and HBI*

| FIM+FAM Item | Mann-Whitney U | Sig. (2-tailed) |
|---|---|---|
| **HBI Worse than TBI** | | |
| Feeding | 613.0 | .021 |
| Grooming | 645.0 | .041 |
| Bathing | 555.5 | .010 |
| Toilet Transfers | 640.0 | .040 |
| Bath Transfers | 554.0 | .027 |
| Car Transfers | 574.5 | .022 |
| Walking/Wheelchair | 578.0 | .047 |
| Stairs | 565.0 | .037 |
| **TBI Worse than HBI** | | |
| Emotion | 490.0 | .006 |
| Attention | 536.0 | .024 |

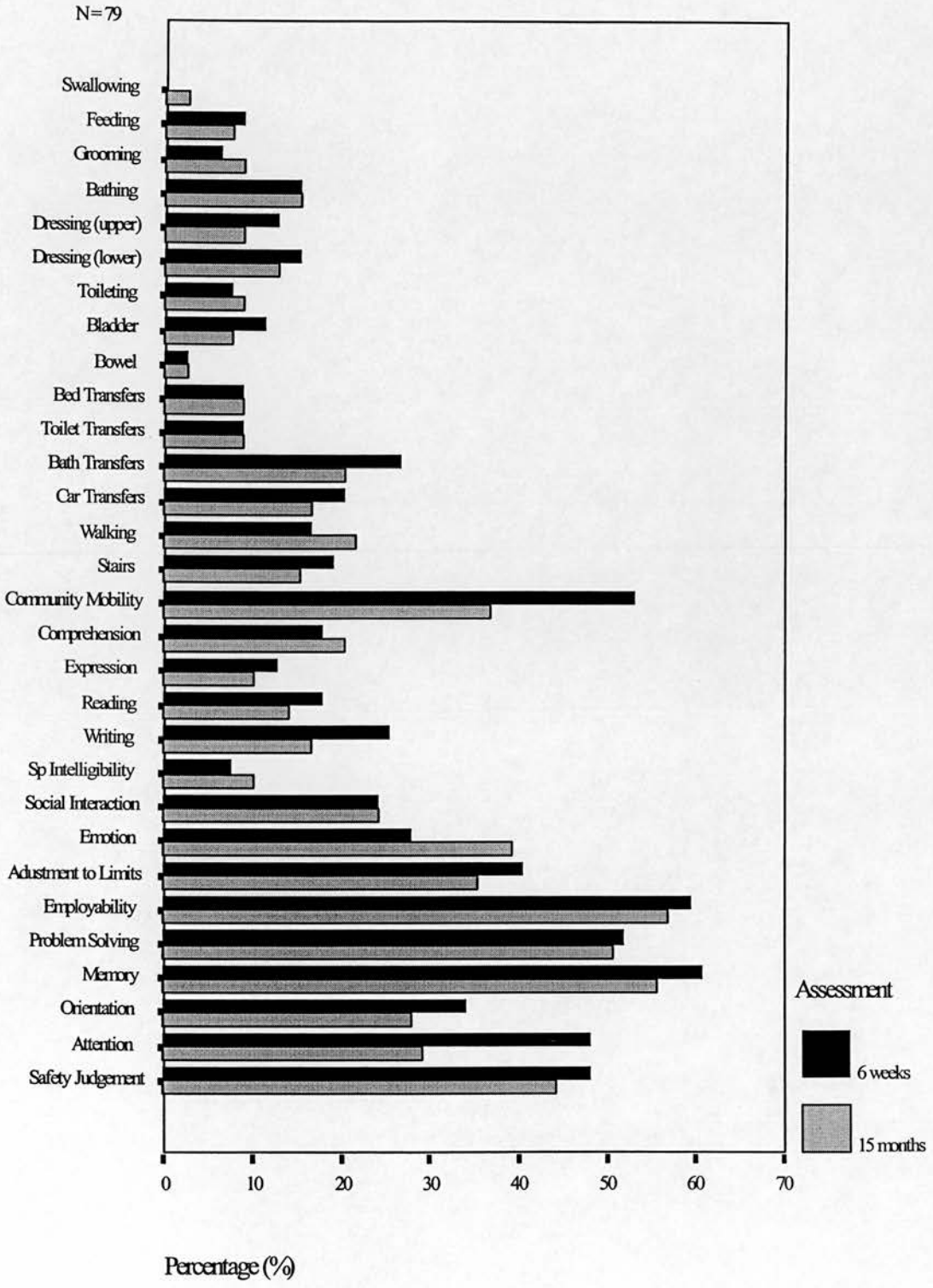
Change over time was more marked than in the Barthel with 22% (n=17) of the sample having worse scores in Physical Function and 42% (n=33) in Psychological Function. Table 5.10-7 shows the numbers deteriorating in each dimension highlighted in the shaded column.

*Table 5.10-7: Change in FIM+FAM dimension score between 6 week and 15 month assessments*

| | Negative Differences | | Positive Differences | | Tied Scores | |
|---|---|---|---|---|---|---|
| ADL | 14 | 18% | 18 | 23% | 47 | 59% |
| Continence | 4 | 5% | 11 | 14% | 64 | 81% |
| Transfers | 12 | 15% | 18 | 23% | 48 | 62% |
| Locomotion | 16 | 20% | 30 | 38% | 33 | 42% |
| Communication | 22 | 28% | 32 | 40% | 28 | 32% |
| Psychosocial | 34 | 43% | 37 | 47% | 5 | 10% |
| Cognition | 26 | 33% | 36 | 46% | 17 | 21% |

It can be seen that in each separate dimension, the majority of patients have either maintained their level of function or improved. Further, the percentage of subjects requiring help on most FIM+FAM items had decreased (Figure 5.10-5).

*Figure 5.10-5: Percentage of patients requiring help on individual FIM+FAM items at 15 months and six weeks*



However, a substantial number of each diagnostic group have lower scores than at six weeks (Table 5.10-8) with a greater percentage of the HBI group deteriorating in ADL, Transfers and Locomotion, and proportionately more of the TBI group deteriorating in the Psychosocial dimension.

*Table 5.10-8: Proportion of TBI and HBI with lower FIM+FAM subscale scores at 15 months*

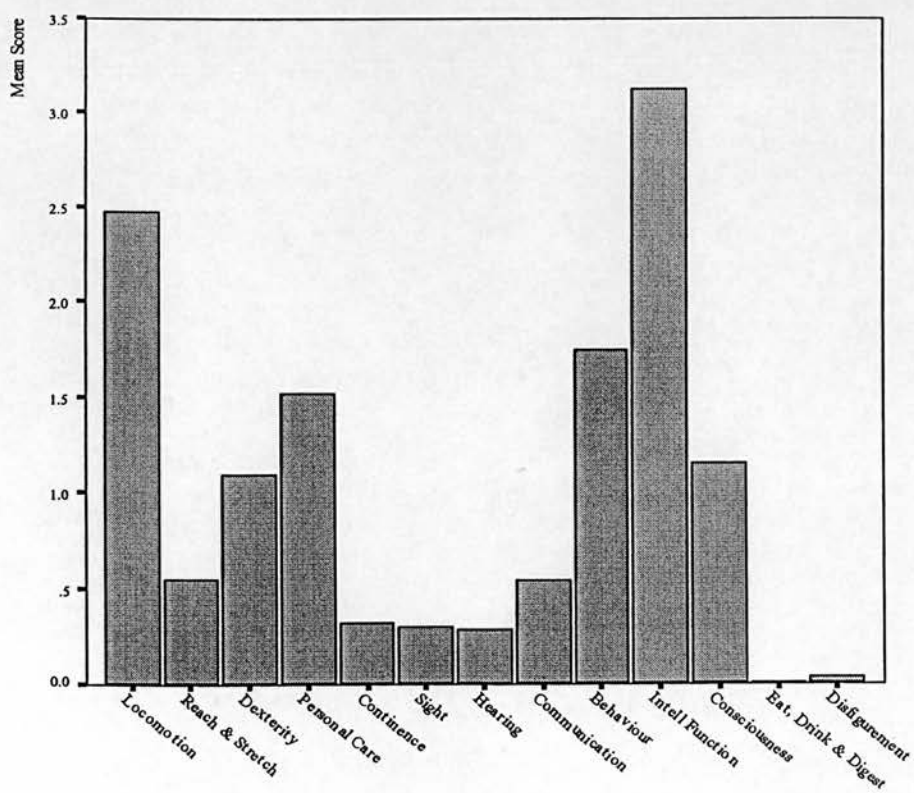
| | TBI (n=47) | | HBI (n=32) | |
|---|---|---|---|---|
| ADL | 3 | 6% | 11 | 34% |
| Continence | 2 | 4% | 2 | 6% |
| Transfers | 3 | 6% | 9 | 28% |
| Locomotion | 8 | 17% | 8 | 25% |
| Communication | 13 | 28% | 9 | 28% |
| Psychosocial | 23 | 48% | 11 | 34% |
| Cognitive | 16 | 34% | 10 | 31% |

The apparent difference in proportions changing according to type of injury was significant for ADL ($\chi^2$=8.401, p=0.004) and Transfers ($\chi^2$ =5.4, p=0.02) as one might expect from Table 5.10-5.

### 5.10.2(iii) The OPCS

At the six week assessment, locomotion, behaviour and personal care showed most functional deficit. At the 15 month assessment, that situation remains (Figure 5.10-6) although there is a slight ( but non-significant) decrease in the scores achieved by the group as a whole.

*Figure 5.10-6: OPCS dimension scores at 15 month follow-up*



However, the two diagnostic groups differed in Personal Care (Mann Whitney U=543.0, p=0.005) with a less significant difference on Locomotion. The significant difference that existed between the groups at six weeks in behaviour and intellectual function no longer exists, although in the case of behaviour, the difference falls just below a significant level (Table 5.10-9).

*Table 5.10-9: Difference between HBI and TBI on OPCS dimensions at 15 months*

| | Mann Whitney U | Sig. (2-tailed) |
|---|---|---|
| Locomotion | 567.50 | .047 |
| Personal Care | 543.00 | .005 |
| Behaviour | 570.00 | .058 |

Thirty people (38%) have a worse (higher) total score on the OPCS at 15 months with no significant difference according to type of injury. However, significant differences were found in how each diagnostic group changed on dimensions. Given the weighted scores used in the OPCS, it is possible to use the Wilcoxon test rather than being limited to a sign test to measure this change as shown in Table 5.10-10 below. Again it must be borne in mind that multiple testing leads to approximately a 30% chance that one of these findings is spurious at the $p<0.05$ level.

*Table 5.10-10: Difference in OPCS Dimensions score according to type of injury*

| | Type of Brain Injury | | | |
|---|---|---|---|---|
| | TBI | | HBI | |
| Wilcoxon Signed Ranks Test | Z | Sig. (2-tailed) | Z | Sig. (2-tailed) |
| Locomotion | -1.28[b] | .201 | -1.17[b] | .243 |
| Personal Care | -1.41[b] | .158 | -.85[c] | .396 |
| Behaviour | -2.42[c] | .016 | -.42[c] | .673 |
| Intellectual Function | -1.81[b] | .070 | -2.03[b] | .042 |
| Consciousness | -.42[b] | .677 | -2.21[c] | .027 |
| OPCS OSS | -1.26[b] | .209 | -.09[c] | .927 |

b. ranked difference indicates improved at 15 months

c. ranked difference indicates worse at 15 months

There has been a significant level of deterioration in behaviour at 15 months for the TBI group and in seizure activity (as measured by the Consciousness dimension) for those with HBI. The change in Intellectual Function for the HBI group is significant where it is not so for the TBI group. However, in order to compare how scores have changed according to injury, a Mann Whitney test is required (Table 5.10-11).

*Table 5.10-11: Difference in extent of change in OPCS between TBI and HBI groups*

| Mann Whitney | U | Sig. (2-tailed) |
|---|---|---|
| Locomotion | 720.5 | .716 |
| Personal Care | 575.5 | .018 |
| Behaviour | 665.0 | .361 |
| Intellectual Function | 690.0 | .524 |
| Consciousness | 579.5 | .012 |
| OPCS OSS | 676.0 | .448 |

The variables where the change is significantly different according to type of injury, are Personal Care and Consciousness.

### 5.10.2(iv) ERSS

The level of handicap or medico-social dysfunction as measured by the ERSS remains at a similar level to the six week assessment score for the population as a whole, and there is no significant difference in the total or subscale scores between the TBI and HBI groups (Table 5.10-12).

*Table 5.10-12: ERSS scores at 15 months*

| | | N | | | Std. | | | Percentiles | |
|---|---|---|---|---|---|---|---|---|---|
| | | Valid | Mean | Median | Deviation | Min | Max | 25 | 75 |
| TBI | ERSS (6 weeks) | 47 | 11.57 | 11 | 4.37 | 4 | 22 | 8.00 | 15.00 |
| | ERSS (15 months) | 47 | 10.43 | 11 | 7.04 | 0 | 25 | 4.00 | 16.00 |
| HBI | ERSS (6 weeks) | 32 | 11.88 | 11 | 5.35 | 3 | 25 | 8.00 | 15.50 |
| | ERSS (15 months) | 32 | 11.31 | 10 | 6.69 | 0 | 27 | 7.00 | 16.75 |

The ERSS at 15 months has changed significantly with more improved (n=45) than deteriorated ranks (n=27) (sign test z = -2.00, p=0.045).

When looking at the four subscales in the ERSS, the greatest change is in the Support subscale with half the group (n=40) receiving less assistance than at six weeks and 14 (18%) receiving more. Although almost half the group have improved scores in the 'Activity / Inactivity' dimension (n=36, 46%), over a quarter have worse scores, indicating more restricted scope and level of activity than at six weeks after discharge. The number of worse scores in 'Social Interaction / Isolation' and 'Effect of Symptoms on Lifestyle' shows a similar pattern with 32% and 25% having deteriorated respectively. For the HBI group the number of improved scores in each dimension is greater than or equal to those who have deteriorated. However, for the TBI group, the number who have deteriorated in 'Social Interaction / Isolation' exceeds those who have improved.

### 5.10.2(v) Summary of change in profile of functional deficit at 15 months

The total scores on each disability measure and on the ERSS indicate that as a group, the level of functional deficit is similar at 15 months to that experienced at six weeks. However, on ADL and Mobility subscales, there is a trend for the TBI group to be less disabled than the HBI group whereas at six weeks there was no difference. This appears largely due to improvements made by the TBI group whilst the HBI group's level of dependence in these activities has remained the same.

In measures of psychological functioning, the difference between the TBI and HBI group is less clear cut. Similar proportions in each group improve and indeed deteriorate on these items in the FIM+FAM . However, on the OPCS Intellectual Function dimension, the HBI group have improved whereas the TBI have not changed.

In terms of psychosocial functioning, the TBI group appear to be more likely to have deteriorated at 15 months and are certainly requiring more assistance than the HBI group. This is also reflected in the level of 'Social Interaction / Social Isolation' subscale on the ERSS where 34% of the TBI group have worse function than at six weeks in contrast to 28% of the HBI group.

Although the profile of disability for the population as a whole is similar to that at six weeks after discharge, there have been a number of areas where change has occurred. In order to investigate this, the functional deficit at 15 months will be investigated in the context of variables that might be predictive including early deterioration.

## 5.11 Relationship of injury severity to functional status at 15 months

As at six weeks, the GCS severity categories did not relate to any of the measures of outcome for the group as a whole. Scores on all measures except the Barthel differed significantly according to severity on PTA categories (Table 5.11-1).

*Table 5.11-1: Relationship of Injury Severity on PTA to functional status at 15 months*

| Kruskal Wallis Test | Chi-Square | df | Asymp. Sig. |
|---|---|---|---|
| Barthel | 5.72 | 3 | .1262 |
| OPCS - OSS | 12.72 | 3 | .0053 |
| FIM+FAM Physical Function | 12.58 | 3 | .0056 |
| FIM+FAM Psychological Function | 18.85 | 3 | .0003 |
| ERSS | 15.53 | 3 | .0014 |
| GOS | 13.06 | 3 | .0045 |

The relationship between severity and the outcome variables remains strong for the TBI group, including a stronger relationship to the Barthel score. However, for the HBI group the relationship is in weaker than at six weeks (Table 5.11-2).

*Table 5.11-2: Spearman's rho of PTA Severity and functional status at 15 months related to injury*

| | | Barthel | OPCS OSS | FIM+FAM Physical Function | FIM+FAM Psychological Function | ERSS | GOS |
|---|---|---|---|---|---|---|---|
| TBI (n=47) | PTA Severity | -.40** | .52** | -.56** | -.61** | .55** | -.55** |
| HBI (n=31) | PTA Severity | -.02 | .11 | .06 | -.25 | .01 | -.03 |

**. Correlation is significant at the .01 level (2-tailed).

## 5.12 Relationship between deterioration at six weeks and functional status at 15 months

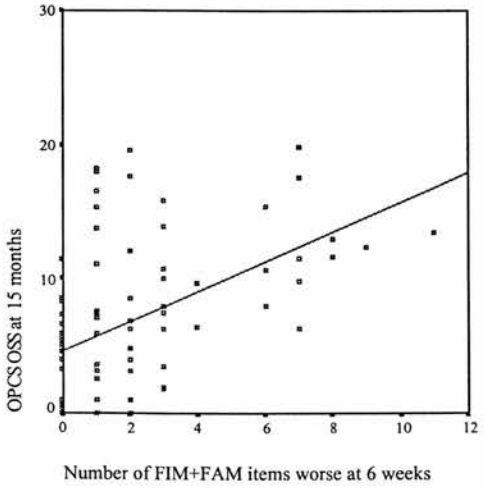
Those subjects who deteriorated on one or more FIM+FAM items between discharge and six weeks had significantly greater levels of deficit on both the OPCS and ERSS at 15 months (Table 5.12-1).

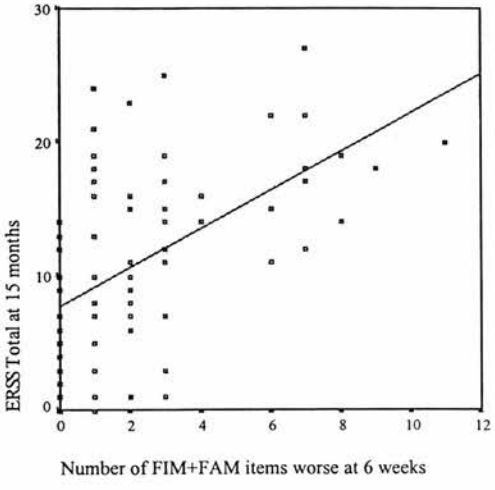
*Table 5.12-1: Level of functional deficit in relation to deterioration at six weeks*

| Mann-Whitney U test | U | Asymp. Sig. (2-tailed) |
|---|---|---|
| Barthel | 501.0 | .006 |
| OPCS - OSS | 269.5 | <0.001 |
| FIM+FAM Physical Function | 377.5 | .001 |
| FIM+FAM Psychological Function | 293.0 | .000 |
| ERSS | 289.0 | .000 |
| GOS | 351.0 | .000 |

Further analysis was carried out to investigate whether deterioration early after discharge contributed to successful prediction of functional deficit at 15 months. The number of items where deterioration had occurred on the FIM+FAM had a linear relationship with the OPCS score and the ERSS score at 15 months (Figure 5.12-1) so these two outcomes can therefore be explored using linear regression.

*Figure 5.12-1: Relationship between deterioration at six week and functional level at 15 months*



As indicated in section 5.11, severity on PTA is linked to functional outcome. Therefore a regression model was examined using PTA severity categories, and the number of items where deterioration occurred at six weeks, as the independent variables (Table 5.12-2).

*Table 5.12-2: Linear regression of ERSS score at 15 months*

| Standardised Coefficient | Beta | t | Significance |
|---|---|---|---|
| (Constant) | | 0.09 | 0.932 |
| Post Traumatic Amnesia Severity Group | 0.22 | 2.31 | 0.024 |
| Number of items worse on FIM+ FAM at six weeks | 0.52 | 5.54 | 0.000 |

The 'deterioration variable' had the most significant predictive role of the two, and the model accounted for 32% of the variance in the ERSS score. As might be anticipated from the strong relationship between the ERSS and OPCS, including the OPCS score from the six week assessment increased the predictive power of the model with 57% of the variance in ERSS score accounted for. However, whilst the effect of severity is removed, that of the 'deterioration variable' remains significant (Table 5.12-3).

*Table 5.12-3: Linear regression of ERSS score at 15 months including disability measure*

| Standardised Coefficient | Beta | t | Significance |
|---|---|---|---|
| (Constant) | | 0.81 | 0.42 |
| Post Traumatic Amnesia Severity Group | 0.04 | 0.54 | 0.59 |
| Number of items worse on FIM+ FAM at six weeks | 0.25 | 2.91 | 0.005 |
| OPCS OSS at six weeks | 0.60 | 6.66 | 0.000 |

## 5.13 Perceived health and functional status

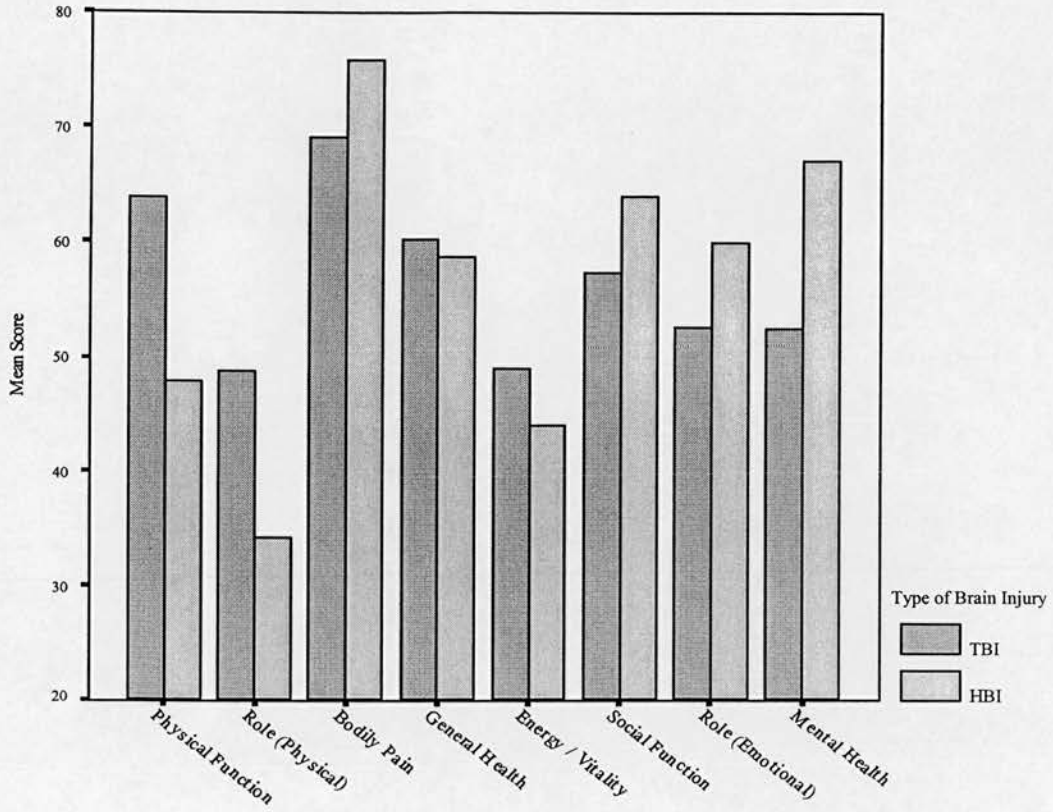
Of the 79 patients seen, 72 completed the SF-36 questionnaire providing their view of their health. Fifty-two people (70%) completed it without help, 9 had help from another person within the home and 11 requested assistance from the researcher. The scores of those who required assistance to complete the questionnaire tended to be lower than those who self completed. Although the disparity in group size makes comparisons difficult, differences across the groups in a number of dimensions were significant using Kruskal Wallis test (Table 5.13-1).

*Table 5.13-1: Difference on SF-36 scores if help required to complete*

| | Physical Health | Role (Physical) | Bodily Pain | General Health | Energy / Vitality | Social Function | Role (Emotion) | Mental Health |
|---|---|---|---|---|---|---|---|---|
| Chi-Square | 15.01 | 7.43 | 6.38 | .95 | 1.25 | 10.56 | .23 | 3.08 |
| df | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 2 tailed Sig. | .001 | .024 | .041 | .623 | .535 | .005 | .893 | .214 |

The perceived health of the TBI and HBI groups differed on Physical Function (Mann-Whitney U=441.5, p=0.03) and Mental Health (U=442.5, p=0.02) (Figure 5.13-1).

*Figure 5.13-1: Perceived Health*




The SF-36 Physical Function score correlated most strongly with the functional assessment results (Table 5.13.2). The measure that had the weakest relationship with the SF-36 dimensions was the Barthel Index.

*Table 5.13-2: Relationship of functional status to perceived health on SF-36*

| Spearman's rho | Barthel | OPCS OSS | FIM Total | FIM+FAM Total | ERSS | GOS |
|---|---|---|---|---|---|---|
| Physical Health | .57** | -.70** | .75** | .74** | -.76** | .69** |
| Role (Physical) | .31** | -.53** | .53** | .53** | -.50** | .45** |
| Bodily Pain | .03 | -.39** | .38** | .38** | -.35** | .34** |
| General Health | .01 | -.34** | .33** | .36** | -.41** | .34** |
| Energy / Vitality | .09 | -.21 | .31** | .31** | -.35** | .28* |
| Social Function | .24* | -.54** | .57** | .60** | -.61** | .56** |
| Role (Emotion) | .01 | -.31** | .33** | .33** | -.29* | .27* |
| Mental Health | .04 | -.30* | .42** | .47** | -.46** | .36** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Severity on PTA categories is also significantly related to perceived health in two of the dimensions (Table 5.13-3).

*Table 5.13-3: Relationship of injury severity to perceived health on SF-36*

| Spearman's rho | PTA |
|---|---|
| Physical Health | -.18 |
| Role (Physical) | -.30** |
| Bodily Pain | -.25* |
| General Health | -.18 |
| Energy / Vitality | -.15 |
| Social Function | -.22 |
| Role (Emotion) | -.11 |
| Mental Health | -.21 |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

The strongest relationship between functional measures and the SF-36 was in the Physical Function, Role (Physical) and Social Function dimension scores.

## 5.14 Other results of the 15 month assessment

### 5.14.1 Services involved at 15 months

Of the 79 people who were followed up at 15 months, the majority (n=53, 67%) were still being seen by a member of health or social services regularly (monthly or more frequently). Twenty-five of these were being seen by just one professional, most frequently the GP (n=17).

As a result of the assessment, 18 people were referred on to a health or social services professional, again most commonly the GP (n=10). In addition, eight people were referred to Headway, and 24 people were referred to services such as benefits advisory services, housing or voluntary sector groups other than the local Headway group.

### 5.14.2 Carer perspective at 15 months after discharge

Of the 79 patients followed up at 15 months after discharge, 73 (92%) were able to be seen with the support person who had been available at the six week assessment The majority of these were spouses (n=35, 48%) or parents (n=26, 36%) and were aged 40 to 49 years of age.

### 5.14.3 The Relative's Questionnaire (RQ)

The sequelae reported by relatives on the RQ were similar to those at six weeks(Table 5.14-1). The proportion reporting problems had reduced significantly in four domains: subjective symptoms, memory, language and dependency. There is no significant difference between the number of problems reported by carers of either diagnostic group at 15 months, except for emotional disturbance where more carers of TBI report difficulties (Mann-Whitney U=444.0, p=0.011).

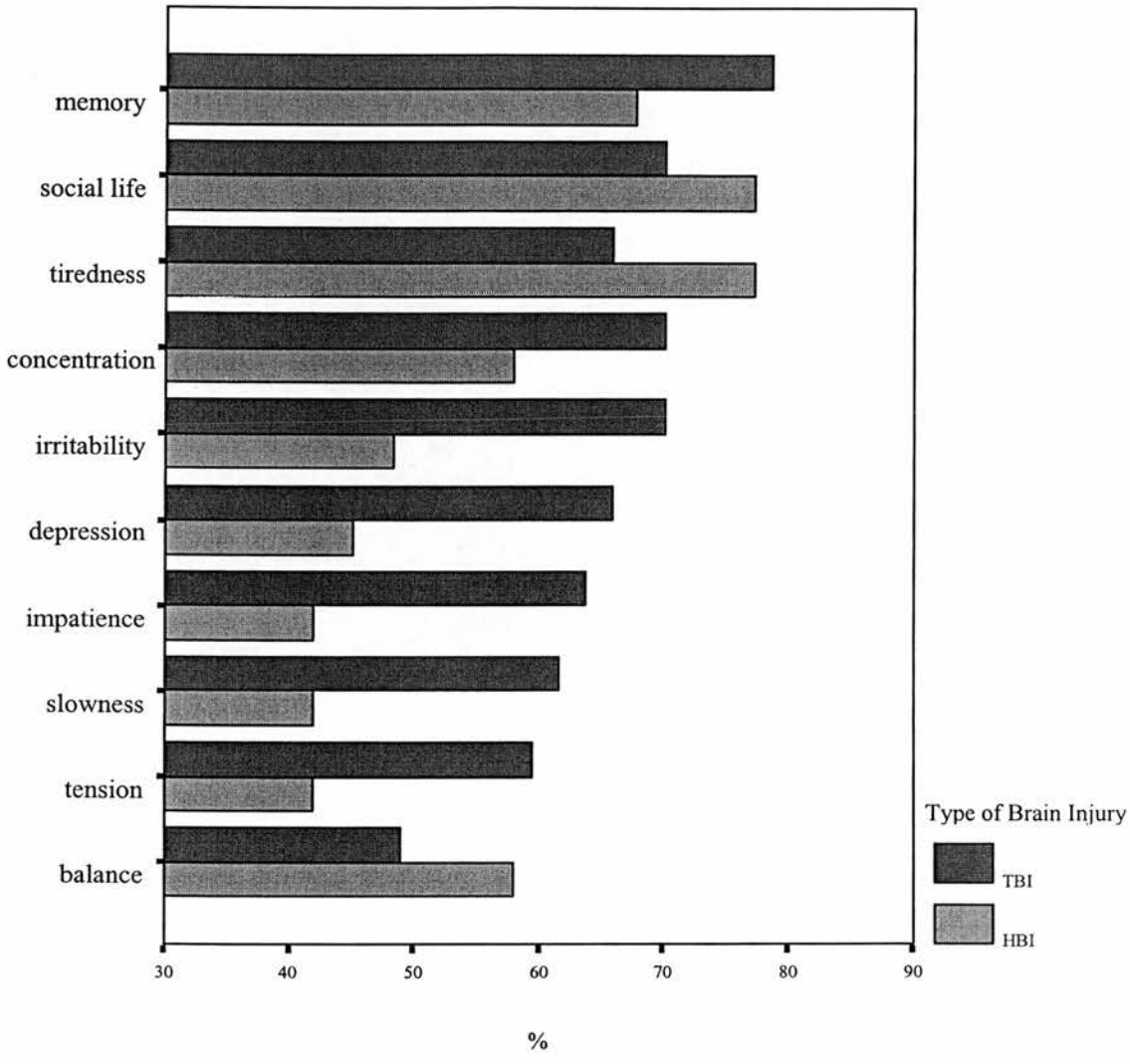
*Table 5.14-1: Frequency of problems on RQ reported by carers*

| | Number reporting difficulties | % | Number reporting more problems at 15 months | Number reporting fewer problems at 15 months | Sign Test - Significance of change |
|---|---|---|---|---|---|
| Physical Symptoms | 63 | 86 | 15 | 16 | |
| Subjective Symptoms | 67 | 91 | 7 | 19 | .031 |
| Emotional Disturbance | 59 | 81 | 13 | 13 | |
| Disturbed Behaviour | 50 | 68 | 9 | 8 | |
| Language | 38 | 52 | 2 | 10 | .039 |
| Memory | 51 | 71 | 1 | 14 | .001 |
| Dependency | 58 | 79 | 3 | 16 | .004 |
| Social Behaviour | 58 | 79 | 1 | 6 | |

The proportion reporting a greater number of problems at 15 months than at six weeks is similar in each diagnostic group except in the case of Physical Symptoms. On this dimension, more in the HBI group noted deterioration (n=10, 31%) than did the carers of TBI (n=5, 11%) ($\chi^2$=4.65, p=0.031).

Three carers did not identify any difficulties on the RQ and the median number of problems reported was 20 (IQR 9-30). There was no statistical difference in the total number of problems identified by the carers of people with TBI or HBI. Figure 5.14-1 highlights the most frequently reported individual items on the RQ.

*Figure 5.14-1: Most frequently reported problems on RQ at 15 months*




The difference in the number of problems reported by carers in each diagnostic group was significantly different on five individual items where, in each case, carers in the TBI group reported more problems. Caution must be used in interpreting the findings given multiple testing and small numbers for some items such as outbursts of violence (n=6) (Table 5.14-2) .

*Table 5.14-2: Number of individual items reported as changed since injury according to type of injury*

| Mann Whitney | U | p | TBI (n=45) | | HBI (n=28) | |
|---|---|---|---|---|---|---|
| | | | n | % | n | % |
| Outbursts of temper | 498.0 | .016 | 26 | 58 | 8 | 29 |
| Outbursts of violence | 635.5 | .045 | 6 | 13 | 0 | 0 |
| Depression | 577.0 | .029 | 31 | 69 | 12 | 43 |
| Childish behaviour | 535.5 | .012 | 17 | 38 | 3 | 11 |
| Sudden mood changes | 501.0 | .026 | 22 | 49 | 6 | 21 |

Table 5.14-3 shows the relationship of the number of items in each RQ dimensions to injury severity and functional deficit at 15 months.

*Table 5.14-3: Spearman rank correlation of number of RQ items with severity and functional deficit*

| | PTA Severity | | OPCS OSS | | ERSS | |
|---|---|---|---|---|---|---|
| | TBI | HBI | TBI | HBI | TBI | HBI |
| Physical | .32 | -.13 | .76** | .69** | .77** | .72** |
| Subjective | .33** | -.07 | .50** | .44** | .64** | .41* |
| Emotion | .30** | -.34 | .41 | .32 | .54** | .36 |
| Behaviour | .26** | .03 | .32* | .43 | .46** | .35 |
| Language | .50** | .16 | .52** | .48** | .65** | .35* |
| Memory | .53** | .23 | .74** | .52** | .80** | .47* |
| Dependency | .45** | -.09 | .75** | .73** | .86** | .87** |
| Social Behaviour | .24 | .01 | .51* | .63** | .66** | .70** |
| Total | .45** | -.01 | .70** | .71** | .83** | .73** |

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

### 5.14.4 Carer Strain

The Carergiver Strain Index was used to record not just whether problems were present, but explored whether carers felt distressed because of the difficulties involved in providing care. Sixty-six of the 73 carers (90%) seen at 15 months after discharge, returned the questionnaire. Seventy-nine percent (n=52) listed that at least one item caused them distress with the median number of items being 3.5 (of a possible 12). The number of items causing distress did not correlate with injury severity but did to the level of functional deficit on those measures reflecting cognitive and psychosocial strain (Table 5.14-4).

*Table 5.14-4: Relationship of Caregiver Strain to functional deficit*

| Spearman rho | Caregiver Strain (number of items) |
|---|---|
| Barthel | -.24 |
| OPCS OSS | .46** |
| FIM | -.49** |
| FIM+FAM | -.49** |
| ERSS | .50** |
| GOS | -.43** |
| FIM+FAM - Physical | -.23 |
| FIM+FAM Psychological | -.52** |

**. Correlation is significant at the .01 level (2-tailed).

The number of items recorded on the Caregiver Strain Index at 15 months was significantly greater when deterioration had occurred between the six week and 15 month assessment on the OPCS and ERSS scores (Table 5.14-5).

*Table 5.14-5: Caregiver Strain Index according to deterioration in level of function at 15 months*

| **OPCS (six weeks to 15 months)** | **Median Number Items** | **Mann-Whitney U test** |
|---|---|---|
| No Deterioration | 6 | |
| Deterioration | 3 | U=313.5, p=0.005 |

| **ERSS (six weeks to 15 months)** | **Median Number Items** | **Mann-Whitney U test** |
|---|---|---|
| No Deterioration | 6 | |
| Deterioration | 2 | U=317.0, p=0.004 |

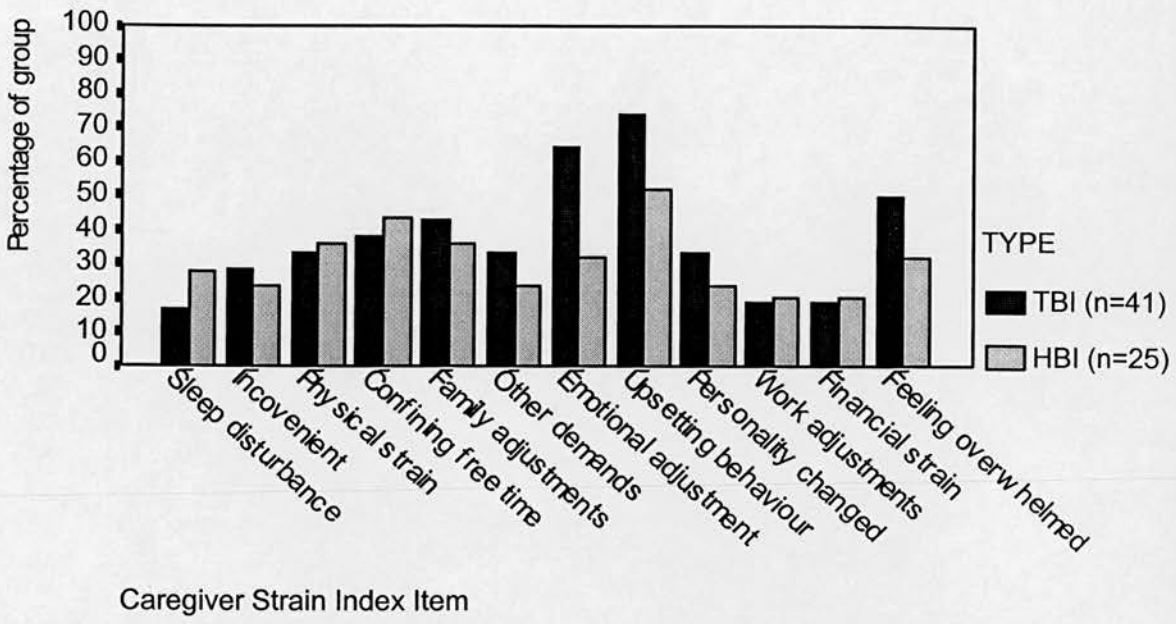
Further, the number of items on the Carer Strain Index was also significantly greater for those who had deteriorated on the FIM+FAM between six weeks and discharge (Table 5.14-6).

*Table 5.14-6: Caregiver Strain Index according to early deterioration in level of function at six weeks*

| **FIM+FAM (Discharge to six weeks)** | **Median Number Items** | **Mann-Whitney U test** |
|---|---|---|
| No Deterioration | 2 | |
| Deterioration | 4 | U=346.0, p=0.044 |

There was no significant difference between the two diagnostic groups in the total number of items recorded on the Caregiver Strain Index although a greater number of carers of TBI survivors reported difficulty in having to make emotional adjustments and coping with upsetting behaviour than HBI carers ($\chi^2$=5.32, p=0.021 and $\chi^2$=4.88, p=0.043 respectively) (Figure 5.14-2).

*Figure 5.14-2: Items reported as causing most distress by injury on Caregiver Strain Index*




## 5.14.5 Perceived Health of Carers at 15 months

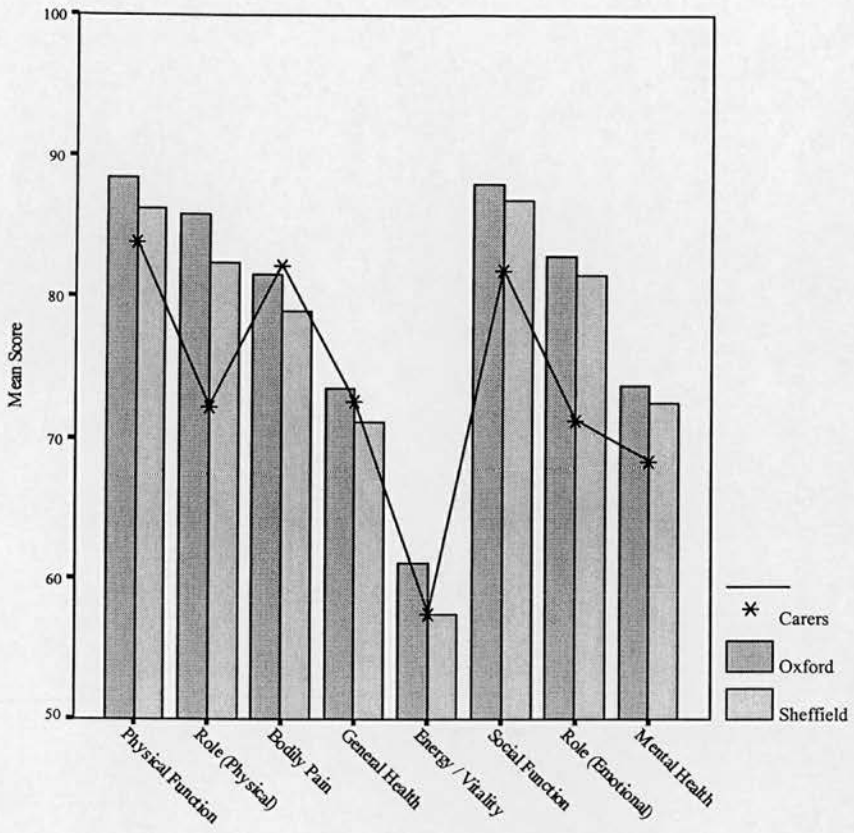
Each carer was asked to complete the Short Form 36 (SF-36) as a measure of perceived health (Ware and Sherbourne, 1992). Sixty-six of the 73 (90%) of the carers seen at 15 months after discharge returned the questionnaire. The results are shown in Table 5.14-7.

*Table 5.14-7: SF-36 results for carers at 15 months*

| SF-36 Dimension | Mean | 95% CI for Mean | | SD | Range |
|---|---|---|---|---|---|
| **Physical Function** | 83.91 | 78.11 | 89.71 | 23.22 | 5-100 |
| **Role - Physical** | 72.27 | 62.69 | 81.84 | 38.35 | 0-100 |
| **Bodily Pain** | 82.28 | 75.91 | 88.65 | 25.49 | 0-100 |
| **General Health** | 72.75 | 66.97 | 78.53 | 23.14 | 5-100 |
| **Energy/Vitality** | 57.73 | 51.82 | 63.65 | 23.67 | 5-100 |
| **Social Function** | 81.95 | 75.62 | 88.29 | 25.37 | 12.5-100 |
| **Role - Emotion** | 71.35 | 61.75 | 80.95 | 38.43 | 0-100 |
| **Mental Health** | 68.44 | 63.13 | 73.75 | 21.25 | 8-100 |

The SF-36 demonstrates lower perceived health in a number of dimensions for carers than that reported in either the general UK population in the Oxford Healthy Life Study (Wright et al, 1992) or the Sheffield study (Brazier 1992). For role limitations due to physical or emotional problems, carers scored respectively 14 and 11 percentage points lower than the general population in a similar age range (Figure 5.14-3).

*Figure 5.14-3: SF-36 scores for carers.*



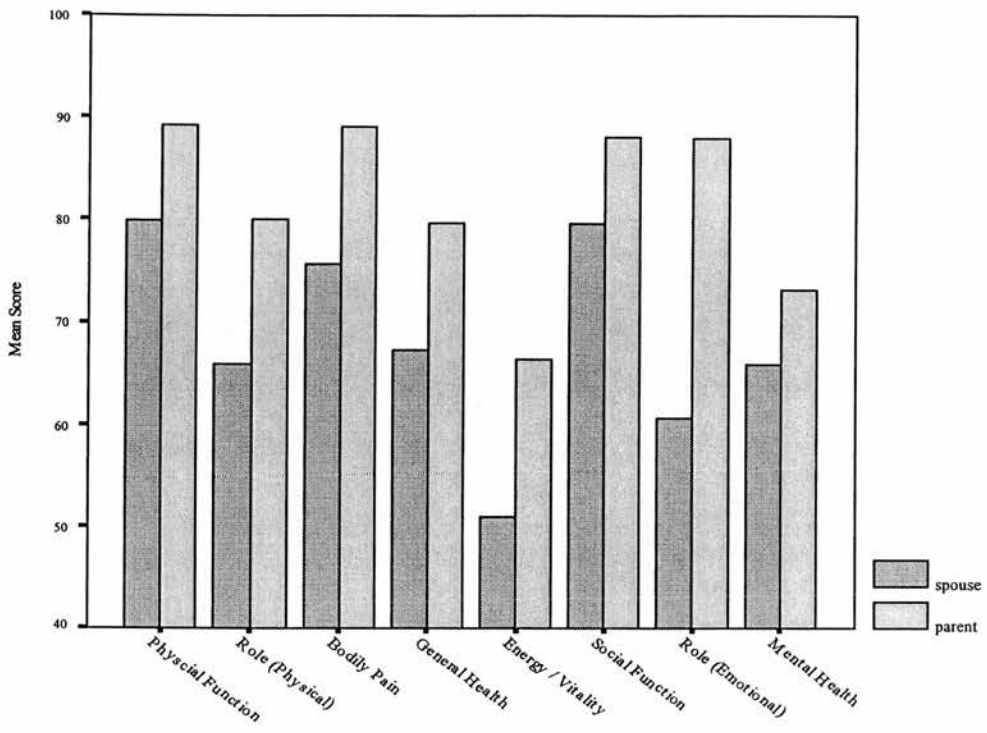

Scores on SF-36 dimensions were similar for both TBI and HBI carers although the HBI group had a tendency to lower scores in Physical Functioning and the TBI group in Mental Health (Table 5.14-8). There was no significant difference between these scores using Mann-Whitney U test.

*Table 5.14-8: SF-36 scores for carers of TBI and HBI*

| | | | 95% Confidence Interval for Mean | | | | |
|---|---|---|---|---|---|---|---|
| | Type | Mean | Lower Bound | Upper Bound | Median | Std. Deviation | Interquartile Range |
| Physical Function | TBI | 86.50 | 80.12 | 92.88 | 95.00 | 19.94 | 20.00 |
| | HBI | 79.58 | 67.85 | 91.31 | 95.00 | 27.78 | 31.25 |
| Mental Health | TBI | 65.40 | 58.15 | 72.65 | 68.00 | 22.67 | 36.00 |
| | HBI | 73.50 | 65.92 | 81.08 | 80.00 | 17.96 | 23.00 |

As the majority of carers were either spouses or parents the SF-36 scores in these two groups was explored (Figure 5.14-4).

*Figure 5.14-4: SF-36 scores for carers [spouses(n= 35) and parents (n=24)]*




The difference between groups was significant in the majority of SF-36 dimensions, with spouses reporting worse health than parents (Table 5.14-9).

*Table 5.14-9: Difference in SF-36 between Parents and Spouses*

| | Mann-Whitney U | Sig. (2-tailed) |
|---|---|---|
| Physical Function | 298.5 | .033 |
| Role (Physical) | 339.5 | .103 |
| Bodily Pain | 288.0 | .014 |
| General Health | 281.5 | .027 |
| Energy/Vitality | 273.5 | .014 |
| Social Function | 303.0 | .027 |
| Role (Emotion) | 249.0 | .003 |
| Mental Health | 348.5 | .180 |

The majority of spouses were aged 50-60 years (n=14, 40%) whilst the majority of parents were aged 40 to 50 years (n=17, 71%). The SF-36 scores for these two age groups were therefore compared but no significant difference was found on any dimension.

### 5.14.6 Relationship between perceived health of carers, injury severity and functional deficit

The carers' SF-36 scores were not related to severity categories on either the GCS or PTA. However, the SF-36 dimensions of Energy/Vitality and Mental Health related significantly to the residual functional deficit at 15 months in their relative on a number of measures (Table 5.14-10).

*Table 5.14-10: Relationship between injury severity, functional deficit at 15 months and Carers' SF-36*

| Spearman's rho | PTA | Barthel | OPCS OSS | FIM | FIM+FAM | ERSS | GOS |
|---|---|---|---|---|---|---|---|
| Physical Function | .02 | -.03 | -.09 | .02 | .04 | -.12 | .22 |
| Role (Physical) | .05 | -.08 | -.02 | .01 | .00 | -.06 | .16 |
| Bodily Pain | .06 | .11 | -.10 | .06 | .05 | -.07 | .16 |
| General Health | .04 | .09 | -.23 | .17 | .17 | -.20 | .21 |
| Energy/Vitality | .10 | .15 | -.30* | .27* | .27* | -.31* | .26* |
| Social Function | .04 | .11 | -.24 | .21 | .20 | -.17 | .22 |
| Role (Emotion) | .04 | .20 | -.26* | .17 | .15 | -.18 | .11 |
| Mental Health | .08 | .22 | -.36** | .31* | .32** | -.33** | .24 |

*. Correlation is significant at the .05 level (2-tailed).

**. Correlation is significant at the .01 level (2-tailed).

In addition, the perceived health of carers differed according to whether there had been deterioration in level of function between six weeks and 15 months. There was a trend for the carers' SF-36 scores to be lower (reflecting lower perceived health) in the group where deterioration had occurred on the OPCS, ERSS and the FIM+FAM Psychological subscale, but not on the FIM+FAM Physical subscale. These differences were significant in a number of dimensions as shown in Tables 5.14-11,12 and 13.

*Table 5.14-11: Carer's perceived health and deterioration on OPCS between six weeks and 15 months*

| SF-36 Dimesnion | OPCS OSS at 15 months compared with 6 weeks | Mean | Median | Std. Deviation | Percentiles 25 | 75 |
|---|---|---|---|---|---|---|
| General Health * | Worse (n=27) | 65.19 | 67.00 | 25.39 | 50.00 | 87.00 |
| | Not Worse (n=39) | 77.39 | 83.50 | 20.38 | 67.00 | 95.00 |
| Energy/Vitality* | Worse (n=27) | 48.52 | 50.00 | 23.49 | 30.00 | 70.00 |
| | Not Worse (n=39) | 63.08 | 65.00 | 22.87 | 45.00 | 80.00 |
| Role (Emotion)* | Worse (n=27) | 56.79 | 66.67 | 39.02 | 33.33 | 100.00 |
| | Not Worse (n=39) | 79.82 | 100.00 | 36.79 | 66.67 | 100.00 |
| Mental Health* | Worse (n=27) | 60.00 | 64.00 | 21.91 | 40.00 | 76.00 |
| | Not Worse (n=39) | 73.74 | 84.00 | 19.07 | 64.00 | 88.00 |

*. Mann Whitney U $p<0.05$

*Table 5.14-12: Carer's perceived health and deterioration on ERSS between six weeks and 15 months*

| | ERSS Score at 15 months compared with 6 weeks | Median | Std. Deviation | Percentiles 25 | 75 |
|---|---|---|---|---|---|
| Energy/Vitality* | Worse (n=30) | 57.50 | 24.72 | 23.75 | 70.00 |
| | Not Worse (n=36) | 62.50 | 21.55 | 46.25 | 80.00 |
| Mental Health* | Worse (n=30) | 64.00 | 23.37 | 40.00 | 84.00 |
| | Not Worse (n=36) | 80.00 | 17.51 | 64.00 | 87.00 |

*. Mann Whitney U $p<0.05$

*Table 5.14-13: Carer's perceived health and deterioration on FIM+FAM Psychological Function between six weeks and 15 months*

| Variables | Change in FIM+FAM Psychological Function | Mean | Median | Std. Deviation | Percentiles 25 | 75 |
|---|---|---|---|---|---|---|
| Energy/Vitality** | Worse (n=29) | 46.90 | 45.00 | 21.23 | 30.00 | 65.00 |
| | Not Worse (n=37) | 65.14 | 70.00 | 23.32 | 55.00 | 80.00 |
| Social Function* | Worse (n=29) | 73.79 | 77.50 | 29.65 | 53.75 | 100.00 |
| | Not Worse (n=37) | 86.89 | 100.00 | 20.80 | 75.00 | 100.00 |
| Mental Health** | Worse (n=29) | 56.28 | 64.00 | 22.75 | 40.00 | 72.00 |
| | Not Worse (n=37) | 77.41 | 84.00 | 14.49 | 66.00 | 88.00 |

**. Mann Whitney U $p<0.005$

*. Mann Whitney U $p<0.05$

Lower scores were also found on the carers' SF-36 scores at 15 months for the group who had deteriorated on the FIM+FAM at six weeks (n=43) than for those who had not (n=23). These differences were significant, or approaching significance for Energy and Vitality (Mann Whitney U=342.0 , p=0.04) and Mental Health (U=352.5, p=0.055).

## Summary

This completes the results section for the first part of the thesis. Examining disability at six weeks and 15 months after discharge from rehabilitation. The study population comprised 54 patients with TBI and 35 with HBI. Males outnumbered females threefold in the TBI group with equal representation of the sexes in the HBI group. The HBI subjects were on average 20 years older than the TBI subjects (mean ages for TBI and HBI : 36 and 56 years respectively). The majority in both groups were categorised as having severe injuries. Other demographic details such as length of stay in acute and rehabilitation units, employment status, premorbid health and cause of injury have been presented.

The chapter has examined how the functional deficits as evaluated using the nine measures summarised in Table 4.3-4, changed between the time of discharge and the subsequent assessments, six weeks and 15 months later. There was a ceiling effect on all measures, reducing sensitivity at lower levels of disability. This was most pronounced on the Barthel Index. The relative strengths and weaknesses of the measures

have been highlighted in the chapter and associated publications (McPherson et al 1993, Pentland and McPherson 1994, McPherson et al 1996, McPherson et al 1997).

The relationship between disability and handicap has been explored by comparing the disability measures, in particular the OPCS, with the ERSS findings. There was a close relationship between the two measures across all levels of disability with the OPCS score accounting for around 70% of the variance in the total ERSS score.

As predicted, levels of disability are maintained or reduced on the total scores of the FIM+FAM but, in the majority of subjects, individual item scores indicated deterioration at six weeks after discharge. A number of factors such as prolonged hospital stay and greater functional deficit at discharge were significant predictors of deterioration. Logistic regression models to predict deterioration were improved by including variables such as age, severity of injury and premorbid function as gauged by years of education. The analysis highlighted the difficulty and imprecision in prognostication regarding functional outcome.

At fifteen months the majority of the group had maintained their level of function or improved. However, the profile of disability for this group remains complex with the majority having persistent difficulties in their everyday function. Further, those who had deteriorated early after discharge had greater levels of 'handicap' at 15 months, even when the actual level of function had been taken into account.

In addition to seeking the views of a relative / carer to ensure a comprehensive assessment of the functional deficit at the level of the individual patient, those aspects which the relative found most difficult to deal with have been documented and the subjective view of the carers' health was also sought. A frequent report from carers was that they found the time after leaving hospital difficult to cope with and the majority sought information across a broad range of issues. The perceived health of the primary carers of brain injured people was compromised when compared with normative data.

The next two chapters address these findings by describing and evaluating an intervention to assist patients and their families deal with the difficulties here described in the post discharge period.

# ROLE OF OUTREACH NURSE IN ASSISTING CONTINUING REHABILITATION AFTER DISCHARGE

## 6.1 Background and rationale of the intervention study

It is now accepted that difficulties for people after a significant head injury change, and for some, may even increase over time. The previous chapter suggests that in this study, a reasonably high proportion of people after severe HBI as well as TBI showed evidence of deterioration in functional status soon after discharge from inpatient rehabilitation. This early deterioration appeared to be linked to increased difficulties in the longer term for both the brain injured person and their family. In addition, a high proportion of the patients expressed a marked level of boredom and inactivity, and both patients and families expressed a need to have more information and support in the early weeks after discharge.

The findings of the descriptive study brought up a number of issues that could not be addressed without further investigation. These included whether the apparent deterioration in functional state could be prevented, and whether provision of support and information would actually be seen to be beneficial by the patient, their carer and indeed the other professionals involved when addressed in a standardised fashion.

It was therefore decided to take the study into a second stage, exploring the impact of an intervention in the weeks after leaving hospital. This chapter describes the follow-up intervention and the methodology of the study to explore its impact.

## 6.2 Follow-up after discharge from inpatient care and outcome

It is usual and advocated as best practice to provide some form of follow-up after inpatient care for those who have experienced a moderate or severe brain injury (Medical Disability Society, 1988). However, the type and extent of follow-up varies considerably between units and indeed patients. It frequently takes the form of a medical review by a neurosurgeon and / or rehabilitation consultant in an outpatient clinic, some weeks after leaving hospital (Pentland and Miller, 1988). Whilst follow-up may be limited to this level of input, ongoing treatment or review may also be carried out by a wide range of professionals such as psychologists, physiotherapists, speech and language therapists, occupational therapists, social workers and others. It is generally assumed that any review process is of benefit to the patient as it provides an opportunity to review progress and to deal with problems that have emerged since discharge. However, there are increasing anecdotal reports that people find this sort of follow-up inadequate and fragmented (Seed, 1994). A recent qualitative study confirms this discontent with the poor co-ordination of services and the lack of relevant information after

discharge from hospital (Hubert, 1995). Although not referring specifically to brain injury, Netting (1990) stated that people with chronic illnesses or disabilities were often unable to access services because of the complexity of the health and social care systems. They suggested the need for someone to act in a co-ordinative role because:

> "services currently available to elderly and disabled people are fragmented, duplicative and difficult to access".

The concept of a case co-ordinator or case manager has been promoted for a number of groups, particularly those people with mental health problems and the frail elderly. Case management has similarly been proposed as being of potential benefit for people with brain injury (Hopkins, 1992; Greenwood et al. 1994).

### 6.2.1 Defining case management

Despite its increasing popularity as a recommended approach, there is no generally accepted definition as to precisely what case management is. For over a decade, it has been accepted as a critical component of mental health services in the United States (Holloway et al. 1995). In the United Kingdom, the term care management, which was intended to be identical to case management but less offensive to users, was introduced in 1993 as a central element of the Government's Care in the Community programme (Department of Health, 1990; Lancet, 1995). Other virtually synonymous titles for case managers are resource managers, resource collaborators and service co-ordinators (Evans, 1984; Davey, 1994).

Case management covers many roles, but there are a number of features that appear common to most descriptions. These include the facts that it is frequently nurses or social workers who provide services (Knollmueller, 1989) and that the assessment and development of care plans tailored for the individual client are integral to the process (Steinberg and Carter, 1983; Goering et al. 1988). However, there are major differences in the detail of the range of responsibilities and activities encompassed in different accounts of case management which as a result cannot, be regarded as a single entity. Many reports and evaluations of new case management developments do not in fact describe what the case manager actually does (Pollock et al. 1993; Shepherd et al. 1996). As a result of poor definition of the exact nature of the role and the paucity of reliable outcome measures (highlighted in Chapter 4), studies of the effectiveness of case management services continue to be unsatisfactory (Davey, 1994; Marshall, 1996; Waterman et al. 1996).

In order to outline the basis of the intervention in this study, different models of case management are now evaluated.

### 6.2.2 Models of case management

Mental health services and the insurance industry have led the way in attempting to improve the definition of case management. Chamberlain and Rapp (1991) identified five different models of case management from those in the literature. This differential remains an extremely useful way to identify the basis of a service, and thus a basis for the tasks carried out. The first model they referred to is a

'clinical' role, whereby the case manager directly intervenes in the clinical management of the patient or client. A second model identified is that of the 'generalist', where the role is predominately concerned with referral onto existing services. The third is one of 'assertive community treatment' where alternative treatment teams are developed and used in place of existing practice. They called the fourth example 'rehabilitation' where the case manager was primarily an educator, and the fifth was labelled a 'strength' model where intervention was predominately about using informal community resources.

An alternate framework identifies three models of case management (Beardshaw and Towell, 1990). The first is that of *social entrepreneurship* where case managers control a budget to purchase services for people. This type of role can be seen in how the responsibilities of local authority social workers and occupational therapists have developed since the government 'reforms' of the health and social services. Secondly, Beardshaw identifies a *service brokerage* model where the case manager holds no funding, but acts rather as an advocate for the client. This second model highlights that although most professional groups would wish to be an advocate for their patients or clients, there is undoubtedly a conflict if they are also the gate-keeper to services. The third concept is based on an extension of the *key worker* role where an existing member of the multidisciplinary team co-ordinates the care of a specific patient. A number of initiatives funded by the National Health Service Management Executive have utilised this model (Department of Health, 1996; Body et al. 1996).

Case management is clearly anything but a unified format of service and merely using the term does not define the intervention. However, a number of key concepts emerge to provide a useful framework by which to structure this specific intervention which, given the professional background of the researcher, has been entitled an Outreach Nurse intervention.

### 6.2.3 Case management as a model for the Outreach Nurse intervention

The frameworks outlined above illustrate that there are three broad areas of case management services which need to be delineated in an intervention:

1. the focus of assessment
2. the role of the professional
3. the relationship between the client and the professional

These are now considered in order to adequately describe the intervention in this study.

#### 6.2.3(i) The focus of assessment in this intervention

The focus of assessment in the intervention study was built on the findings of the descriptive study. That is, the early deterioration in functional level, and the subsequent effects in terms of the individuals perceived health and that of their carer. To that end a similar range of measures was utilised to see whether or not the intervention made any difference at either assessment point (six weeks and 15 months). In addition, the assessment focussed on whether the service was acceptable to interested and involved parties including the patient, their carer and other professionals treating the patients.

### 6.2.3(ii) The role of the professional

The role of the worker was also determined by the findings of the descriptive study. That is, in attempt to address two specific factors:

1. the increased functional deficit and dependency at six weeks which although occurred in less than half of the cohort (at 37%) was felt to be a clinically significant finding
2. the expressed need of both the patient and their family for increased information and support

Two styles of service from Chamberlain and Rapp's model appear most relevant to the role of the professional in this intervention. Firstly, the 'rehabilitation' model whereby the necessary information to empower both the patient and their family is provided and, secondly, the 'generalist' role where referral on to, and communication with other therapists was an explicit focus of management. Using Beardshaw's framework, a mix of the 'key worker' and 'brokerage model' was identified as covering the range of interventions that might be required at different times.

Whilst clearly more complicated than choosing a single model, it seemed important to allow for a combined role to ensure a two-way flow of information. By this, I mean that in addition to the provision of information to the patient and their family, the professionals involved in ongoing management also had appeared to be in need of information. Although not formally measured in the descriptive study, a number of professionals had expressed the view that feedback from the researcher's visits had been of benefit. For those professionals based in the community, this was most frequently in the form of information to them about brain injury and perhaps services provided at a national level of which they were unaware. For those professionals based within the specialist rehabilitation units, information about the home situation was often stated to have been of benefit to their continued treatment.

### 6.2.3(iii) The professional / client relationship

It was clear that the relationship between the professional and the patient and family was to be of great importance in this intervention given the educational and supportive component. Although this is often not explicitly considered in health-care interventions, it has long been recognised that the relationship between a doctor and their patient is vital (Peabody, 1927). More recently it has been suggested that if the relationship between a patient and any health professional is poor, outcomes will be adversely affected (Mechanic, 1992).

Three factors appear in the literature as factors contributing to this relationship being positive when one is hoping to have an educational role. Firstly, that a warm and caring atmosphere should exist, secondly that information should be provided in an understandable way (Stiles et al. 1979, Whitcher-Alagna, 1993) and thirdly, that the level of information provided needs to match the level of information desired by the recipient, as giving too much information can actually increase levels of arousal and stress in patients (Miller and Mangan, 1983). These were therefore adopted as key goals to be aimed for in the relationship between the researcher as the practitioner and the subjects of the intervention group.

### 6.2.4 Domiciliary Nature of the Intervention

In addition to the difficulties arising from lack of follow-up arrangements for the people with brain injury and the poor co-ordination of services, even when reviews are arranged, attendance of patients is notoriously low. Two recent studies cite follow up rates of 25% (Clifton et al. 1993) and 48% (Ponsford et al. 1995). One recommended way to reduce the drop out in research studies is to visit the subjects at home (Brooks et al. 1984). Thus, by designing the intervention as domiciliary in nature, it was hoped to encourage compliance with the service. As the focus of the intervention was directed at the family unit, rather than the brain injured person alone, visiting at home at a convenient time had the added advantage of making contact with carers more likely. Seeing people in comfortable, familiar home surroundings also helped ensure the warm and friendly atmosphere recommended for information giving as described above.

## 6.3 Aims and hypotheses

The main aims of the second phase of the study were to investigate whether a home based intervention, i.e. an outreach nurse intervention, had any immediate effect on alleviating the difficulties occurring in the early weeks after discharge and whether any beneficial effect was maintained at over one year post injury. The first assessment took place at six weeks after discharge as in the descriptive study. The longer-term assessment was carried out at 15months after injury in order to fit in with other studies utilising the same population to avoid confusion and 'over-assessment'.

The priorities of this intervention were to provide support to the patient and their carer with information regarding the nature of the injury and recovery process and guidance as to how to optimise any change in function. It was also planned to communicate relevant findings to other practitioners actively involved in the individual's ongoing management.

The specific hypotheses of this part of the study were that:

1. the level of disability in the intervention group will be maintained or reduced at 6 weeks post discharge
2. any improvement in function will be greater for the intervention group than for controls
3. satisfaction regarding information provided will be greater in the intervention than control group
4. the perceived health of the persons with brain injury and their carers will be unchanged or improved whereas that of the control group will be worse at 15 months after injury
5. the service will be acceptable to patients and their families
6. the service will be acceptable to other professionals

The corresponding null hypotheses to be disproved were that:

1. the level of disability at six week follow-up will not be maintained in the intervention group
2. the degree of improvement in level of disability from discharge to six weeks will be the same for the intervention and the control group
3. the level of satisfaction with information in both groups will be the same
4. any change in perceived health for the persons with brain injury and their carers will be unrelated to membership of the intervention group
5. the service will not be acceptable to patients and their families
6. the service will not be acceptable to other professionals

## 6.4 Methodology and procedure

The following section describes the methodology used in selection of the intervention and control groups as well as the specifics of the intervention and the assessment procedures.

### 6.4.1 Measures

The measures chosen are described in Chapter 4. In this intervention study, all the functional measures [Barthel Index (BI), OPCS Disability Scale, Functional Independence Measure (FIM) and Functional Assessment Measure (FIM+FAM), Edinburgh Rehabilitation Status Scale (ERSS) and Glasgow Outcome Scale (GOS)] were applied at the three intervals: on discharge, six weeks after discharge and 15 months after injury. Again using the same methods utilised in the descriptive study, evaluations of the carer's perspective were performed at six weeks and 15 months after injury.

In addition, an anonymous questionnaire was administered to patients and carers with a separate questionnaire given to professionals, in each case seeking their view of the service. Copies of these questionnaires are in Appendix (x) and (xi). Both questionnaires were based on information that had emerged during the descriptive study and were developed specifically for this study.

The first questionnaire was tested for reliability by administering it to a small sample of patients and their carers who were not included in the intervention study but had been visited in the course of the descriptive study. Between 80 and 90% percent agreement was found in responses after one week.

The questionnaire for professionals was validated by prior consultation with a range of different hospital and community based staff. Their view on which questions were appropriate and comprehensive was sought and where there was a consensus regarding their value, questions were retained. The questionnaire was not tested for reliability. Space was also allowed for comments outside the remit of the questionnaire in order to encourage more full comments from people who felt so inclined. This questionnaire was sent to professionals involved with the patients in the intervention sample on completion of the intervention component of the study.

### 6.4.2 The Intervention

The goals and process of the intervention in terms of the focus of the assessment, the role of the professional and the relationship between the professional have been explored in Section 6.1.2. However, it is important to detail specific components of the intervention, and to that end a framework of 12 axes has been used (Table 6.4-1). This framework has previously been used to describe interventions by rehabilitation nurses in the insurance industry and appeared applicable to the goals and process identified (Thornicroft, 1991).

*Table 6.4-1: The twelve axes of the intervention*

| Axes | Description in the Outreach Nurse Intervention |
|---|---|
| Target population | People who had received a moderate or severe brain injury as a result of trauma or haemorrhage and were discharged to the community from a rehabilitation unit |
| Individual versus team management | The outreach nurse intervention was individual in the sense that she visited the patient alone. She was involved in team management from the point of taking part in case conferences after discharge and liasing with members of the team as required |
| Direct care versus brokerage | Both these aspects were involved - direct care for the educational and supportive aspects of the service, and brokerage for the liaison and advocacy role |
| Intensity of interventions | The intervention group were visited for an hour each week for six weeks after discharge with assessment at the end of that time |
| Degree of budgetary control | The outreach nurse held no budget |
| Health or social service function | The main focus of the intervention was on health in terms of maintenance of function and the provision of support to family members. However, advice and support was also provided to social service employees |
| Status of the case manager | The outreach nurse in this case was a registered nurse, health visitor and held a degree in psychology |
| Specialisation of case manager | The three areas of specialisation in this intervention were a) community nursing b) neurological rehabilitation and c) assessment and measurement of function |
| Staff client ratio | All interventions were carried out by one person (KM), and at any one time up to four families were involved in the six week intervention |
| The patient client participation | The patient and their family were actively involved in directing the intervention in terms of goals set, information provided and information passed to others. This was considered essential in order that the goals and information be relevant to the patients situation |
| Point of contact | All interventions took place in the persons home and local area |
| Level of intervention | The intervention was primarily at the level of the individual family unit, with extension to other services as and when required. |

### 6.4.3 Case selection

It was clear that in order to complete the study within the timeframe of this research project, the recruitment phase would need to be limited to approximately eight to ten months. Whilst this would allow only relatively small numbers to be recruited, it was accepted for the following reasons:

1. it was achievable within the existing funding and timeframe
2. it would meet the needs of a pilot investigation of such an intervention
3. it might therefore establish whether a larger study could be recommended

Recruitment to the intervention study began after a period of three months had elapsed since the last recruitment to the descriptive study. This time allowed consideration of the initial findings from the descriptive study so as to inform the design of the intervention. As with the descriptive study, consecutive patients admitted to the national brain injury rehabilitation unit were recruited to the study and consent sought.

A major consideration in the design of the study was how best to allow the intervention to be evaluated. It has long been suggested, and is now widely accepted that the optimum research practice for evaluating the impact of a treatment intervention is a randomised control trial (Sackett and Rosenberg, 1995; Sackett et al. 1996). However, with the anticipated sample size in this study, true randomisation was clearly not possible. A number of methodologies were considered, including a series of single case studies. However, there are serious limits to the generalisation of findings from this sort of study, particularly when the population has such varied sequelae. Indeed, the proliferation of case series and the lack of control trials has been stated as one of the factors in the lack of effective treatment strategies in a number of clinical areas (Deyo, 1993).

For this reason, statistical advice was sought prior to the study in order to determine a methodology that might be able to allow appropriate and meaningful comparison between a control and intervention group with a small sample.

#### 6.4.3(i) The Minimisation Method

Various methods of stratification may be adopted in order to control the membership of intervention or control groups in a smaller study where randomisation might well result in two groups that were in essence quite different. Stratification of the sample works well in situations where one is clear on the causative factors and importantly, the number of factors is limited to prevent over-stratification. However, in the case of functional recovery after brain injury, stratification would entail using a huge range of factors that have been identified as possibly influencing long-term outcome. It would therefore result in an unwieldy and most worryingly, still probably unbalanced sample due to the number of strata (Pocock, 1983).

Minimisation is a specific stratification method described by Pocock to address this situation by combining together a series of factors in order to allocate subjects to different treatment groups. The aim is to balance the number of patients as the study progresses by allocation to the group based on

the number in each group for each level of each patient factor. The group with the smallest sum of marginal totals is the treatment option for the next patient, or when numbers are equal, by randomisation. It is inevitable that such a method might be complex to understand and organise, however, with a little practice it became quite easy and quick to use and an explanation of the method now follows.

*6.4.3(i)a The Minimisation Method Explained*

On entry, the characteristics of the patient in a number of predetermined areas are scored as either membership of the category or not. For instance, in the case of brain injury and functional outcome a category such as nature of injury might have two levels, 'focal injury' or 'no focal injury'.

The first patient is allocated to a treatment group by randomisation and their characteristics recorded, most easily on a series of index cards with a card for each level in the characteristics. One then totals up the occurrence of such characteristics for each treatment group and allocates the next patient to that with the smaller sum of marginal totals. Pocock usefully illustrates this method by reference to a group of 80 patients who have been recruited to a study on breast cancer. The research team have identified patient characteristics linked to outcome, such as whether they are ambulatory or non-ambulatory, over 50 years or under 50 years and so on. Pocock presents a table where the number of patients in each treatment are shown according to these characteristics, thus each patient appears for each category as illustrated in Table 6.4-2:

*Table 6.4-2: Example of minimisation method*

| Factor | Level | No on Treatment A | No on Treatment B |
|---|---|---|---|
| Performance status | Ambulatory | 30 | 31 |
| | Non- Ambulatory | 10 | 9 |
| Age | Under 50 years | 18 | 17 |
| | over 50 years | 22 | 23 |
| Disease-free interval | less than 2 years | 31 | 32 |
| | | 9 | 8 |
| Dominant metastatic lesion | Visceral | 19 | 21 |
| | Osseous | 8 | 7 |
| | Soft tissue | 13 | 12 |
| **Sum of marginal totals** | | **76** | **77** |

In this example, the next patient would be allocated to Treatment A because the sum of marginal totals is smaller. As each patient is recruited to the study, the numbers are amended and entry of the next patient allocated in a similar way.

Clearly the fact that characteristics need to be recorded prior to entry to the study might be seen to be a limit of the method. However, allocation to each group is dictated by the preceding subject and this gives less room for manipulation of the subjects into a group to suit the researcher and thus biasing results if time of entry to the study is fixed by some external criteria. Nevertheless, an element of

randomisation, or chance allocation, is useful when the study is small and being co-ordinated by the one researcher. To that end, entry to the study was based on notification of discharge date by secretarial staff and further, random tables were used to allocate subjects with a ¾ probability of being assigned to the smaller sum of marginal totals and a probability of ¼ to the larger.

The range of factors affecting outcome in brain injury are of course extremely wide ranging and complex, particularly when the outcome to be measured is not limited to mortality. For the purpose of this study, factors were pragmatically chosen based on those suggested to be useful and perhaps predictive in the literature (Jennett et al. 1979; Rappaport et al. 1989; Katz and Alexander, 1994; Saveland and Brandt, 1994; Dikmen and Machamer, 1995). The majority of characteristics used for this process had two levels as shown in Table 6.4-3.

*Table 6.4-3: Characteristics used for minimisation method*

| **Characteristic** | **Group 1** | **Group 2** | **Group 3** | **Group 4** |
|---|---|---|---|---|
| Type of Injury | TBI | HBI | | |
| Presence of Focal Injury | Yes | No | | |
| PTA | <4 weeks | ≥4 weeks | | |
| Initial GCS Motor Score | Unknown | 1-3 | 4-6 | |
| Years of Education | >12 years | 11 or 12 years | 10 years | At school |
| Length of stay in acute unit | > 24 days | ≤ 24 days | | |
| Definite drug / alcohol history | Yes | No | | |
| Age | ≥ 40 years | < 40years | | |

### 6.4.3(ii) Background to the source of the sample

Patients were recruited from those receiving in-patient treatment at the Scottish Brain Injury Rehabilitation Service, Edinburgh in the same manner as the descriptive study (see Section 4.2.3).

### 6.4.3(iii) Inclusion and Exclusion Criteria

The sample consisted of patients discharged consecutively over an eight month period - March 1994 to November 1994. This allowed all follow up visits to be completed by January 1996. Inclusion and exclusion criteria were the same as for the descriptive study.

All patients and their relatives meeting the inclusion criteria, were asked by ward staff if they would accept visits by the researcher at home in the weeks after discharge from hospital. The purpose of the study was explained as an attempt to find out how the early weeks after discharge had been for the person who had the injury and for their family. If they agreed, the researcher was notified and the patient was entered into the study using the minimisation method described in Section 6.4..3(i).

This resulted in a sample of 43 patients however, one subject initially allocated to the intervention group, changed her mind, resulting in a sample of 42. The patient who decided not to take part in the study was a 21 year-old woman who had a subarachnoid haemorrhage from an Anterior Communicating Artery Aneurysm which was occluded by coil. By the time of discharge, she had good functional recovery with some residual cognitive deficit but wished to have no further involvement with rehabilitation services. She and her family were offered the opportunity to contact either the researcher or other rehabilitation staff in the future if required, but this offer was not taken up.

### 6.4.3(iv) The Assessments

The process of the first stage of the procedure followed the same format as the descriptive study. However, the researcher assessed patients using the functional measures just prior to the patients being discharged from inpatient rehabilitation. An independent assessor, blind to whether the patient was allocated to the intervention or control group, also carried out an assessment using the FIM+FAM measure at discharge and at 15 months post injury. In most cases this was a medical research worker involved in a separate study. However, when this was not possible, a FIM+FAM assessment of a therapist who knew the patient was used.

As with the descriptive study, an information sheet was provided and this included an independent contact name and phone number in case of any concerns they did not feel able to discuss with the researcher. A consent form was also signed.

Patients who were assigned to the intervention group had an appointment made for within ten days of leaving hospital for the researcher to visit for the first time. Thereafter, a further five visits were made in order to provide service as described in Table 6.4-1. Patients who were assigned to the control group were invited to contact the researcher at anytime if they required information or support prior to the visit which was scheduled for six to seven weeks in keeping with the descriptive study. They were invited to contact the researcher at any time if they required information or support prior to this visit.

All interventions were carried out by the researcher (K.M) in the patient's home and whenever possible, another person nominated by the patient (usually a relative) was asked to be present.

Each assessment took approximately one to two hours and consisted of observation of activities complemented by interview data from both the patient and relative.

In addition, self report questionnaires were used and an additional questionnaire on satisfaction with the outreach nurse service was posted to carers 3 months after the six week assessment.

## 6.4.4 Data management and statistical analysis

Data was managed using Paradox Version 4 for Windows, and Excel Version 5.0 for Windows. Data was analysed using SPSS, Version 6 for Windows, and Version 7 for Windows 95.

# RESULTS - THE INTERVENTION STUDY

## 7.1 Introduction

Forty-two subjects were recruited to the intervention study, 23 TBI and 19 HBI. As described in Chapter 6, the sample was selected from a similar pool of patients as the descriptive study. It is not intended to describe the premorbid characteristics, injury details or the disability profiles in as much detail as the descriptive study, but rather to concentrate on the evaluation of the intervention study. To that end, specific aspects of the data have been selected and examined in some detail.

## 7.2 Demographic Details

The study population was similar to that of the descriptive study in terms of residence, with just under half residing in Edinburgh (n=20, 48%). Although a similar proportion of the group as a whole were male (n=23, 55%), the type of injury related to gender was more distinct (Table 7.2-1).

*Table 7.2-1: Sex distribution*

| | TBI | | HBI | |
|---|---|---|---|---|
| | n | % | n | % |
| Male | 19 | 82.6 | 4 | 21.1 |
| Female | 4 | 17.4 | 15 | 78.9 |
| Total | 23 | 100.0 | 19 | 100.0 |

The mean age for the total group was again 43 years with a difference of 20 years between the TBI (mean=32.3, s.d 14.26) and HBI group (mean=56.7, s.d. 11.4). The breakdown of marital status was similar with the majority of TBI single (n=12, 52%) and majority of HBI married (n=13, 68%).

The median LOS in the acute hospital was similar to that of the descriptive study at 25 days (IQR: 16-42). However, LOS in the rehabilitation unit was 47 days (IQR: 18.75 -112). Further investigation shows that almost 30% (n=12) of the study group in this phase of the study had length of stays in the rehabilitation unit of greater than 100 days as opposed to 12% cases in the earlier descriptive study. The TBI group in this part of the study had a longer median rehabilitation stay of 48 days (IQR: 23 - 150) than the HBI group (median=38 days, IQR: 15-98). This difference was not significant (Mann-Whitney U=177.5, p=0.3)

The majority of those eligible for work were employed prior to the injury (Table 7.2.2).

*Table 7.2-2: Employment status*

| | Type of Brain Injury | | | |
|---|---|---|---|---|
| | TBI | | HBI | |
| | Frequency | Percent | Frequency | Percent |
| fulltime | 16 | 69.6 | 7 | 36.8 |
| part-time | 2 | 8.7 | 3 | 15.8 |
| student | 4 | 17.4 | - | - |
| unemployed | 1 | 4.3 | - | - |
| housewife | - | - | 5 | 26.3 |
| retired | - | - | 4 | 21.1 |
| Total | 23 | 100.0 | 19 | 100.0 |

There was a tendency for the TBI group to come from lower socio-economic groups than the HBI (Table 7.2-3), but given the small sample size it would be imprudent to attempt to analyse any difference statistically.

*Table 7.2-3: Social class and type of injury*

| | TBI | | HBI | |
|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent |
| 1 | 2 | 8.7 | 3 | 15.8 |
| 2 | 2 | 8.7 | 4 | 21.1 |
| 3 (non manual) | 6 | 26.1 | 6 | 31.6 |
| 3 (manual) | 5 | 21.7 | 3 | 15.8 |
| 4 | 2 | 8.7 | 3 | 15.8 |
| 5 | 6 | 26.1 | | |
| Total | 23 | 100.0 | 19 | 100.0 |

The majority of the sample had been in good health prior to the brain injury. One woman in the HBI group had a subarachnoid haemorrhage 38 years previously and had also been treated successfully for breast cancer some eight years before this most recent health episode. No other cases were considered to have major health problems.

As with the descriptive study sample, a significant number of the TBI group (n=9, 35%) had an alcohol problem recorded in the medical notes with only one of the HBI noted to have an alcohol problem. This is likely to be an underestimate given the reasons stated in Chapter 5.

## 7.3 Clinical Features of the Group

### 7.3.1 TBI Group

Twenty-three of the sample had experienced a head injury. Most had been pedestrians (n=8, 35%), with almost equal numbers injured in motor vehicle accidents (n=5) and falls (n=6). The median age of each group was similar to that of the descriptive study except in the case of the pedestrians where the median age was 20 years younger at 27.5 years (IQR 10-36). It is interesting to note that for all but one pedestrian, alcohol was noted to have been 'on board' at the time of injury.

Seven patients (30%) had surgical evacuation of haematomas, one of whom had a further operation for hydrocephalus. The remaining fifteen patients did not undergo surgical treatment, eight (35%) having contused lobes and a further five (22%) having diffuse axonal injury with no focal damage.

As in the descriptive study, the majority of patients were classified as having a severe injury using GCS (n=16, 70%), with two patients classified as having a mild injury. Twenty of the patients (87%) had a PTA of longer than four weeks indicating severe damage. The two patients classified as having a mild injury on GCS, had a moderate injury using PTA.

### 7.3.2 HBI Group

Nine (47%) of the HBI group had surgery for a SAH. A further four (21%) had clipping of an aneurysm before the vessels had ruptured. The most frequently occurring aneurysms were ACA and MCA aneurysms (n=4, n=4). The remaining patients presented with a variety of HBI: Three had intracerebral haemorrhages, one of whom underwent surgery to remove a haematoma; two patients had internal capsule haemorrhages and one patient had an AVM that was treated conservatively.

As with the descriptive study, this group of HBI patients ware at the more severe end of the spectrum of injuries as one might expect. In fact, this group were more severely injured than the descriptive study with no patient having a WFNS grading of I (Table 7.3-1).

*Table 7.3-1: WFNS score*

| | | Frequency | Percent |
|---|---|---|---|
| Valid | II | 2 | 10.5 |
| | III | 6 | 31.6 |
| | IV | 7 | 36.8 |
| | V | 4 | 21.1 |
| Total | | 19 | 100.0 |

Although GCS would suggest that two patients had mild injuries, PTA shows a similar pattern to the TBI group with 18 of the patients noted to have a severe injury (12 having a very severe injury).

### 7.3.3 Summary

When compared with the descriptive study, the sample might be considered more severely injured on the basis of initial injury and to have more complicated rehabilitation needs given the longer stay in the rehabilitation unit.

## 7.4 Characteristics of the Intervention and Control Groups

As outlined in Chapter 6, the minimisation method was used to stratify the sample. This section reports on the balance between the groups. Twenty-two patients were recruited to the intervention group and 21 to the control group. With the withdrawal of the one subject, each group comprised 21 patients. Given the lack of a normal distribution for most variables it is most appropriate to use non-parametric statistics in evaluating difference between the two groups.

There was no statistical difference in the number of TBI or HBI allocated to each group ($\chi^2$=0.38, p=0.535) (Table 7.4-1).

*Table 7.4-1: Intervention or control group and type of brain injury*

| | TBI | HBI | Total |
|---|---|---|---|
| Intervention | 13 | 8 | 21 |
| Control | 10 | 11 | 21 |

Other characteristics used to assign subjects to the intervention or control group were explored in order to detect any difference (Table 7.4-2).

*Table 7.4-2: Characteristics of the intervention and control groups*

| | | | | | | IQR | |
|---|---|---|---|---|---|---|---|
| | Condition | n | Median | Minimum | Maximum | 25 | 75 |
| Age | Intervention | 21 | 33.00 | 16 | 74 | 25.50 | 58.50 |
| | Control | 21 | 48.00 | 18 | 69 | 26.50 | 62.50 |
| Acute LOS | Intervention | 21 | 28.00 | 7 | 98 | 16.00 | 55.50 |
| | Control | 21 | 24.00 | 7 | 94 | 15.00 | 36.50 |
| GCS | Intervention | 21 | 8.00 | 3 | 15 | 5.50 | 12.00 |
| | Control | 19 | 7.00 | 3 | 14 | 5.00 | 12.00 |
| GCS Motor Score | Intervention | 19 | 4.00 | 1 | 6 | 3.00 | 6.00 |
| | Control | 18 | 4.00 | 1 | 6 | 3.00 | 5.25 |
| Years of Education | Intervention | 21 | 11.00 | 10 | 18 | 10.00 | 12.00 |
| | Control | 21 | 11.00 | 10 | 15 | 10.50 | 11.00 |

The median age of the intervention group is younger than the control group, but the IQR indicates that this difference is unlikely to be statistically significant and indeed this was the case (Mann-Whitney U=183.5, p= 0.35). The number in each PTA group was similar as shown in Table 7.4-3.

*Table 7.4-3: PTA group according to condition*

| | Moderate 1 to 24hours | Severe 1 to 7 days | Very Severe 1 to 4 weeks | Very Severe >4weeks |
|---|---|---|---|---|
| Intervention | 2 | 3 | 4 | 12 |
| Control | 1 | 4 | 6 | 10 |

The number of subjects with a definite history of alcohol misuse was higher for the control group (n=6) than the intervention group (n=3) but the difference was not significant ($\chi^2$=0.57, p=0.45).

Analysis of the descriptive study indicated rehabilitation stay was predictive of deterioration and therefore that is also explored in Table 7.4-4.

*Table 7.4-4: Rehabilitation length of stay*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| Condition | Median | Minimum | Maximum | 25 | 75 |
| Intervention | 60.00 | 4 | 210 | 20.00 | 135.00 |
| Control | 31.00 | 5 | 220 | 16.00 | 100.00 |

These data indicated that the intervention group stayed longer in rehabilitation than the control group. However, a Mann-Whitney U test indicates that the ranked scores were not statistically different (U=178.5, p=0.29). Given the relationship between rehabilitation LOS and deterioration in functional state outlined in the descriptive study, this was examined further. Although not wholly appropriate given the skewed distribution, parametric analysis using means and confidence intervals indicated considerable overlap in rehabilitation LOS between the two conditions (Table 7.4-5).

*Table 7.4-5: Further exploration of rehabilitation LOS*

| | | Intervention | Control |
|---|---|---|---|
| Mean | | 80.48 | 60.05 |
| 95% Confidence Interval for Mean | Lower Bound | 50.47 | 33.82 |
| | Upper Bound | 110.48 | 86.27 |
| Std. Deviation | | 65.91 | 57.61 |

All but one individual (a woman aged 68 years in the control group who lived alone) were seen with the person identified at six weeks and 15 months as their main support.

*Table 7.4-6: Relationship of carer (n=42)*

| | Intervention | Control | Total |
|---|---|---|---|
| wife | 8 | 4 | 12 |
| husband | 4 | 7 | 11 |
| parent | 7 | 6 | 13 |
| offspring | 1 | 2 | 3 |
| sibling | 1 | 2 | 3 |

## 7.5 Profile of function at discharge

The first assessment of functional status was performed just prior to discharge from the rehabilitation wards. The level of function as reflected by the median total scores on each of the functional measures is illustrated in Table 7.5-1.

*Table 7.5-1: Level of function at discharge (n=42)*

| | | | Percentiles | |
|---|---|---|---|---|
| | Condition | Median | 25 | 75 |
| Barthel | Intervention | 19.00 | 14.00 | 20.00 |
| | Control | 20.00 | 19.00 | 20.00 |
| OPCS | Intervention | 8.40 | 3.65 | 16.55 |
| | Control | 4.45 | 2.00 | 15.18 |
| FIM | Intervention | 115.00 | 91.00 | 118.00 |
| | Control | 117.00 | 93.50 | 121.00 |
| FIM+FAM | Intervention | 183.00 | 142.50 | 192.50 |
| | Control | 178.00 | 144.50 | 197.00 |
| ERSS | Intervention | 15.00 | 10.00 | 20.50 |
| | Control | 14.00 | 7.00 | 20.50 |
| GOS | Intervention | 3.00 | 3.00 | 3.00 |
| | Control | 3.00 | 3.00 | 4.00 |

The median OPCS Overall Severity Score (OSS) indicated a greater level of disability for the intervention group, but this was not significant (Mann-Whitney U=175.0, p=0.25). This contrasts with the FIM+FAM score which indicates the control group had slightly worse function on discharge. Further investigation of this shows that one woman in the control group had a total FIM+FAM score of 55, some 72 FIM+FAM points lower than the next lowest score for the control group and 58 points lower than the lowest score in the intervention group. Excluding her score from analysis results in the two groups having a similar level of dysfunction on discharge on the FIM+FAM. In contrast, excluding her OPCS score has no impact on the median OPCS scores for the two groups.

As the FIM+FAM was assessed by independent assessment at discharge, the level of agreement with the main researcher was investigated and the results are presented in Table 7.5-2.

*Table 7.5-2: Percentage of ratings with total agreement between researcher and external rater*

| FIM+FAM Dimension | Percentage of Ratings in Total Agreement | | Percentage with Difference > 1 Point | |
|---|---|---|---|---|
| | n | % | n | % |
| Swallowing | 40 | 97.6% | | |
| Feeding | 38 | 92.7% | | |
| Grooming | 39 | 95.1% | | |
| Bathing | 36 | 87.8% | 1 | 2.4% |
| Dressing Upper | 36 | 87.8% | | |
| Dressing Lower | 37 | 90.2% | | |
| Toileting | 41 | 100% | | |
| Bladder | 38 | 92.7% | 2 | 4.9% |
| Bowels | 38 | 92.7% | | |
| Bed Transfers | 36 | 87.8% | | |
| Toilet Transfers | 37 | 90.2% | 1 | 2.4% |
| Bath Transfers | 37 | 90.2% | 1 | 2.4% |
| Car Transfers | 38 | 92.7% | 3 | 2.4% |
| Walking | 40 | 97.6% | | |
| Stairs | 38 | 92.7% | | |
| Comprehension | 28 | 71.8% | 1 | 2.6% |
| Expression | 35 | 85.4% | | |
| Reading | 32 | 78.0% | | |
| Writing | 30 | 73.2% | | |
| Speech Intelligibility | 32 | 78.0% | 4 | 9.8% |
| Social Interaction | 30 | 73.2% | 1 | 2.4% |
| Emotion | 36 | 87.8% | | |
| Adjustment to Limits | 31 | 75.6% | | |
| Problem Solving | 32 | 78.0% | | |
| Memory | 27 | 65.9% | 1 | 2.4% |
| Orientation | 30 | 73.2% | 1 | 2.4% |
| Attention | 29 | 70.7% | 2 | 4.9% |
| Safety Judgement | 31 | 75.6% | 1 | 2.4% |
| Employability | 26 | 63.4% | 3 | 7.3% |
| Community Mobility | 26 | 63.4% | 2 | 4.9% |

These findings compare favourably with the results of a previously published inter-rater reliability study of the FIM+FAM (McPherson et al. 1996). The scores from the principal researcher tended to be slightly lower than that of the external rater. In subsequent results, including comparison of the ratings at discharge with those at six weeks post-discharge, it is the principal researcher ratings which are presented to avoid any inaccurate impression of deterioration which might arise if averaged combined ratings were used.

## 7.6 Level of function at six weeks

The median level of function reflected by total scores on each of the measures was similar between the intervention study and the descriptive study . However, as one would expect the IQR is wider in the smaller intervention sample (Table 7.6-1).

*Table 7.6-1: Level of function at six weeks*

| | Intervention Study Sample (n=42) | | | Descriptive Study Sample (n=89) | | |
|---|---|---|---|---|---|---|
| | | Percentiles | | | Percentiles | |
| | Median | 25 | 75 | Median | 25 | 75 |
| Barthel | 20.00 | 17.00 | 20.00 | 20.00 | 19.00 | 20.00 |
| OPCS | 5.70 | 2.08 | 14.25 | 6.50 | 3.00 | 10.20 |
| FIM | 116.50 | 94.75 | 123.00 | 118.00 | 109.50 | 123.00 |
| FIM+FAM | 189.00 | 151.50 | 199.50 | 189.00 | 173.00 | 199.00 |
| ERSS | 14.00 | 9.00 | 20.25 | 11.00 | 8.00 | 15.00 |
| GOS | 3.00 | 3.00 | 4.00 | 3.00 | 3.00 | 4.00 |

As with the score at discharge, the intervention group had higher levels of dysfunction on the OPCS disability measure at six weeks (Table 7.6-2), although there is no significant difference between these scores (Mann-Whitney U=214.0, p=0.87). The control group had higher ERSS scores than the intervention group as opposed to discharge but again this difference is not significant (Mann-Whitney U=217.0, p=0.94).

*Table 7.6-2: Level of function at six weeks according to experimental condition*

| | | | Percentiles | |
|---|---|---|---|---|
| | Group | Median | 25 | 75 |
| Barthel | Intervention (n=21) | 20.00 | 16.50 | 20.00 |
| | Control (n=21) | 20.00 | 19.00 | 20.00 |
| OPCS | Intervention (n=21) | 7.65 | 2.17 | 13.65 |
| | Control (n=21) | 4.70 | 2.05 | 15.18 |
| FIM | Intervention (n=21) | 116.00 | 97.00 | 123.50 |
| | Control (n=21) | 119.00 | 93.00 | 122.00 |
| FIM+FAM | Intervention (n=21) | 189.00 | 153.00 | 201.50 |
| | Control (n=21) | 189.00 | 148.00 | 197.00 |
| ERSS | Intervention (n=21) | 12.00 | 7.00 | 19.00 |
| | Control (n=21) | 14.00 | 7.00 | 19.50 |
| GOS | Intervention (n=21) | 3.00 | 3.00 | 4.00 |
| | Control (n=21) | 3.00 | 3.00 | 4.00 |

## 7.7 Change in level of function at six weeks

In the descriptive study, the nature of change in function was explored in most depth by looking at the change in FIM+FAM score. A similar approach is used for this phase of the study and is augmented by evaluating the change in ERSS score as a broader assessment of function.

### 7.7.1 Change in Function - FIM+FAM

Twenty-two (52%) of the sample had FIM+FAM items which showed deterioration as compared with 67% of the descriptive study. Table 7.7-1 shows that a greater proportion of the control group than the intervention group exhibited evidence of deterioration on the FIM+FAM. This difference falls short of accepted levels of statistical significance ($\chi^2$= 3.4, p=0.06)[1].

*Table 7.7-1: Presence of deterioration on FIM+FAM items according to experimental condition*

| | | Any Items Worse? | |
|---|---|---|---|
| | | No | Yes |
| | Intervention | 13 | 8 |
| | Control | 7 | 14 |
| Total | | 20 | 22 |

Of the 42 subjects, 19 (45%) had fewer items scoring '5 or less' at the six week assessment, suggestive of improvement in functional status. Six people (14%) scored '5 or less' on more items and in 17(41%), there was no change. Whilst the proportion showing improvement was little different to the descriptive study, a smaller percentage showed deterioration, and more subjects had the same number of FIM+FAM dimensions where they were requiring assistance. Whilst Table 7.7-2 indicates that the intervention group made more of a positive gain than the controls, it is not appropriate with the small numbers to test this statistically.

*Table 7.7-2: Number of FIM+FAM items where help required at six weeks compared with discharge*

| | Intervention | Control | Total |
|---|---|---|---|
| same number of items | 8 | 9 | 17 |
| more items | 2 | 4 | 6 |
| less items | 11 | 8 | 19 |

The discharge FIM+FAM Psychological Function score was the most predictive of deterioration on the FIM+FAM in the descriptive study. Whilst being aware that the small sample size reduces the likelihood of finding statistically significant predictors, it is of interest to explore whether being in the intervention or control group impacted on a predictive model of deterioration in this sample. To that end, simple models are explored using logistic regression. The discharge FIM+FAM Psychological Function score

[1] One tailed test used in view of direction of hypothesis.

was not predictive of deterioration on a FIM+FAM item in this sample (Wald = .81, p=0.37). As expected from this result, the model did not produce good separation of those who deteriorated from those who did not, with most of the sample clustered around 0.5 probability (Figure 7.7-1) .

*Figure 7.7-1: Predicted probability of deterioration using discharge FIM+FAM Psychological Function Score*

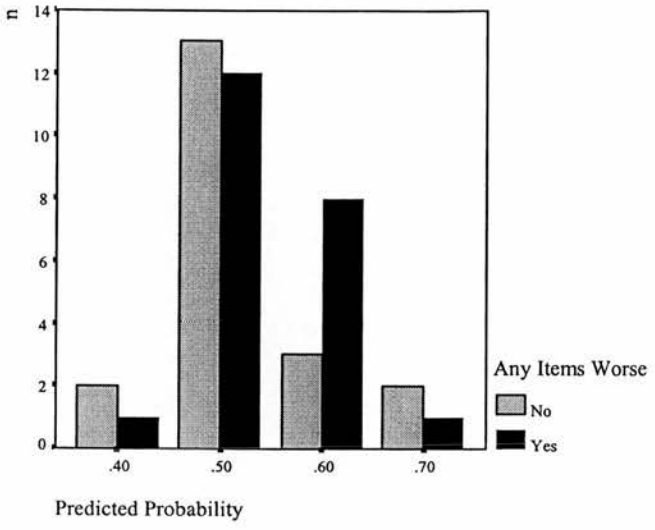
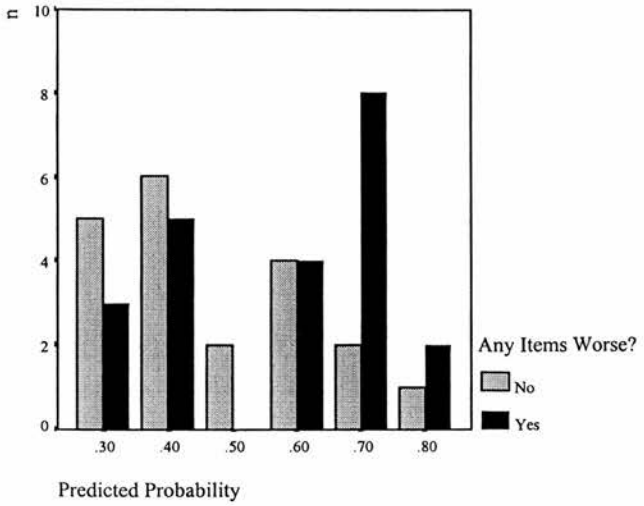


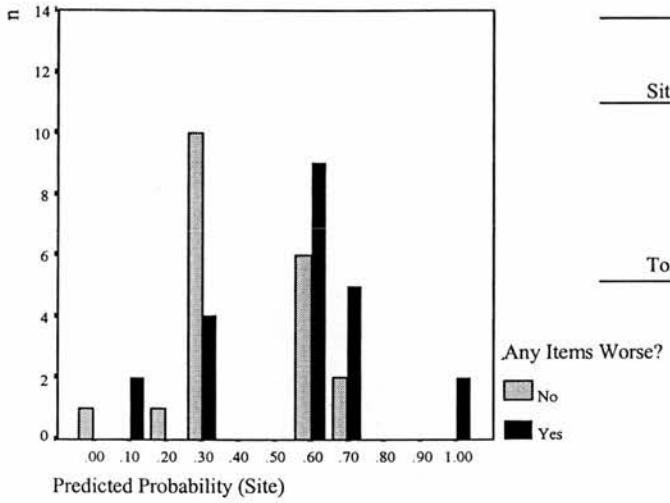

Table 5.8-8 in Chapter 5 highlighted that in addition to FIM+FAM Psychological Function, a number of other variables were significantly, or almost significantly, linked to deterioration. These variables were FIM+FAM Physical Function, Rehabilitation LOS and Acute LOS. However, in the experimental study sample, none of these were significantly related to deterioration. The next step was to explore any effect that the experimental condition (of intervention or control group) may have on a regression model of deterioration. The experimental condition variable almost reached significance as a predictor of deterioration (Wald=3.37, p=0.68, R=-0.15) and, Figure 7.7-2 illustrates that there was improved, albeit imprecise separation according to whether the subject was in the intervention or control group.

*Figure 7.7-2: Predicted probability of deterioration using discharge Psychological Function score and Experimental Condition*



In the descriptive study, the most accurate prediction of deterioration in one FIM+FAM item came from a complex model including Physical and Psychological Function on the FIM+FAM at discharge, sex, age, PTA severity, and years of education. This is now examined for the second study group to see if the model is strengthened. Prior to entry of any of these variables, the only one that was predictive of deterioration was the site of the primary injury (right, left, frontal, occipital or diffuse injury in the case of TBI) (Wald = 10.08, p=0.04, R= 0.19). Those with frontal or diffuse injuries appeared to deteriorate with more frequency ($\chi^2$=0.89, p=0.03) although caution in interpreting this is advisable given the small numbers in some cells (Figure 7.7-3).

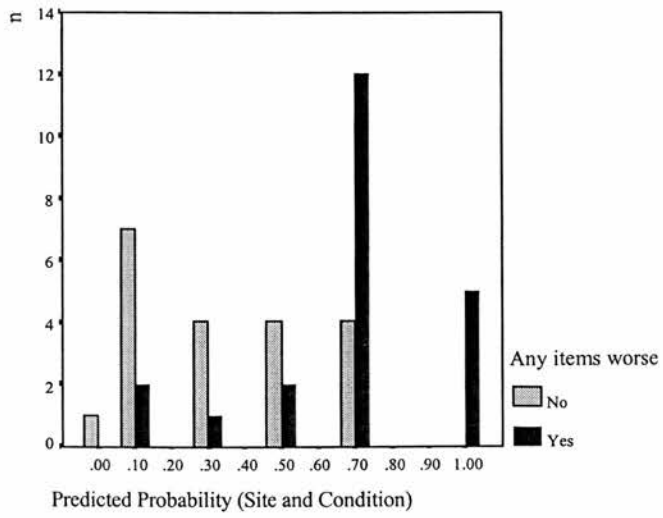
*Figure 7.7-3: Predicted probability of deterioration using site of injury*




| | Any FIM+FAM items worse at 6 weeks | | |
|---|---|---|---|
| Site of Injury | No | Yes | Total |
| Right | 11 | 4 | 15 |
| Left | 6 | 9 | 15 |
| Diffuse | 2 | 5 | 7 |
| Frontal | | 4 | 4 |
| Occipital | 1 | | 1 |
| Total | 20 | 22 | 42 |

Although a stepwise logistic model only includes site of injury (the experimental condition just falling short of significance as being predictive), the following chart of the predicted probabilities shows that including the experimental condition, leads to better separation of the two groups ('deteriorated' and 'not deteriorated').

*Figure 7.7-4: Predicted probability of deterioration using site of injury and experimental condition*



### 7.7.2 Change in Function - ERSS

It has been noted that there was a shift in ERSS scores from discharge to six weeks in the two groups. On discharge, the intervention group had a slightly higher median ERSS scores (Table 7.5-1) but at six week follow-up, this situation was reversed with the control group having slightly higher scores (Table 7.6-2). Although this difference was not significant, the change in ERSS dimension scores may be of interest. The ERSS Activity / Inactivity subscale in particular addresses the patient's ability to initiate, sustain and effectively perform the activities involved in their occupation, domestic role and/or leisure pursuits. The grading is affected by either the failure to undertake or be effective in activities as a result of impairments or disabilities. This is of interest as the intervention in the study directly aimed to help patients improve their level of activity. Thus, an improvement in the ERSS Activity / Inactivity subscale for the intervention group might be hypothesised. In the descriptive study this subscale showed evidence of marked dysfunction (Table 5.5-17). Table 7.7-3 shows the range of scores in each subscale for the intervention study sample at six weeks after discharge. Again the Activity / Inactivity subscale indicated marked dysfunction for both the intervention and control group with no significant difference between the groups.

*Table 7.7-3: ERSS subscale scores at six weeks*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| ERSS Subscale | Experimental Condition | Mean | Median | 25 | 75 |
| Support | Intervention (n=21) | 3.33 | 3.00 | 1.00 | 5.00 |
| | Control (n=21) | 3.43 | 4.00 | 1.00 | 5.50 |
| Activity / Inactivity | Intervention (n=21) | 4.05 | 4.00 | 3.00 | 5.00 |
| | Control (n=21) | 4.10 | 4.00 | 3.00 | 5.00 |
| Social Isolation | Intervention (n=21) | 2.71 | 3.00 | 1.00 | 4.00 |
| | Control (n=21) | 3.19 | 3.00 | 1.00 | 5.00 |
| Effect of Symptoms | Intervention (n=21) | 3.67 | 3.00 | 2.50 | 5.00 |
| | Control (n=21) | 3.38 | 3.00 | 2.00 | 5.00 |

When looking at change since discharge, more of the intervention group showed an improved score and none showed deterioration in comparison to the control group (Table 7.7-4). However, it is inappropriate to test the significance of this result given the small numbers in some cells.

*Table 7.7-4: ERSS Score at six weeks compared to discharge*

| | Condition | |
|---|---|---|
| | Intervention | Control |
| Improved | 7 | 3 |
| Same | 14 | 15 |
| Deteriorated | 0 | 3 |

### 7.7.3 Perceived health of patients at six weeks

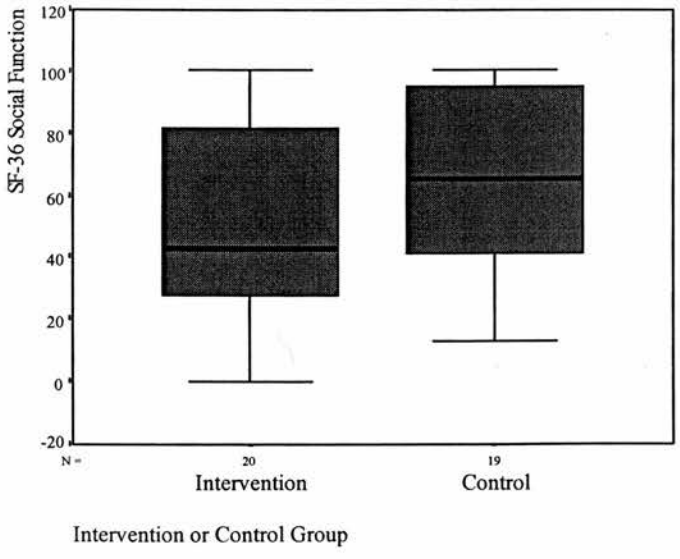
Thirty-nine (93%) of the subjects completed the SF-36 questionnaire. It was not possible for one patient to complete it due to the extent of her communication difficulties and two others did not return the questionnaire.

Non-parametric statistics have been used to explore the SF-36 scores given the sample size. The lowest median score in the eight dimensions was for physical role and the only significant difference between the experimental conditions was in Physical Function, with the Experimental condition having lower scores (Mann-Whitney U=110.5, p=0.025) (Table 7.7-5). Although not significantly different, the median score for social function was lower for the intervention group. This was explored further by using a plot of the mean, standard deviation and extreme values (Figure 7.7-4) where there is marked overlap between the two conditions.

*Table 7.7-5: SF-36 scores for Intervention and Control groups at six weeks.*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Group | n | Median | 25 | 75 |
| Physical Health | Intervention | 20 | 67.50 | 25.00 | 78.75 |
| | Control | 19 | 85.00 | 70.00 | 95.00 |
| Role (Physical) | Intervention | 20 | 25.00 | .00 | 43.75 |
| | Control | 19 | 25.00 | .00 | 100.00 |
| Bodily Pain | Intervention | 20 | 87.00 | 72.00 | 90.00 |
| | Control | 19 | 84.00 | 62.00 | 90.00 |
| General Health | Intervention | 20 | 60.00 | 34.50 | 87.00 |
| | Control | 19 | 77.00 | 62.00 | 87.00 |
| Energy / Vitality | Intervention | 20 | 50.00 | 36.25 | 60.00 |
| | Control | 19 | 65.00 | 35.00 | 80.00 |
| Social Function | Intervention | 20 | 42.50 | 26.25 | 84.38 |
| | Control | 19 | 65.00 | 32.50 | 100.00 |
| Role (Emotion) | Intervention | 20 | 50.00 | 8.33 | 100.00 |
| | Control | 19 | 100.00 | 33.33 | 100.00 |
| Mental Health | Intervention | 20 | 68.00 | 49.00 | 87.00 |
| | Control | 19 | 80.00 | 68.00 | 88.00 |

*Figure 7.7-5: Patient's SF-36 Social Function dimension scores*



## 7.8 Carer perspective at six weeks

Forty-one people completed the Relative Questionnaire (RQ) and the problems reported followed a similar pattern to the descriptive study. A greater proportion of carers in the intervention group reported behaviour and emotional disturbance problems, and a higher percentage of the control group reported memory problems (Table 7.8-1). The number of problems in each area is not significantly different according to experimental condition nor according to type of injury.

*Table 7.8-1: Frequency of problems on RQ reported by carers*

| | Intervention (n=21) | | Control (n=20) | |
|---|---|---|---|---|
| | Number reporting difficulties | % | Number reporting difficulties | % |
| Physical Symptoms | 21 | 100% | 19 | 95% |
| Subjective Symptoms | 21 | 100% | 20 | 100% |
| Emotional Disturbance | 17 | 81% | 11 | 55% |
| Behaviour | 15 | 71% | 11 | 55% |
| Language | 11 | 52% | 12 | 60% |
| Memory | 14 | 67% | 16 | 80% |
| Dependency | 19 | 90% | 19 | 95% |
| Social Behaviour | 19 | 90% | 14 | 70% |

Thirty-seven of the carers returned the Caregiver Strain Index (88%) and the majority reported one or more aspect of providing care as distressing (n=32, 86%). The median number of items reported was four, with no difference in the number reported according to either experimental condition or to the type of injury.

For most of the items, there was little difference in the number of carers reporting distress with the most frequently reported items being strain as a result of 'restriction to free time' (n=20, 54%) and 'feeling completely overwhelmed' (n=16, 43%).

In two items, a difference approaching statistical significance was found. For 'restriction to free time', 13 (68%) of the intervention group, and seven (37%) of the control group reported strain ($\chi^2$= 2.64, p=0.1). For 'financial strain', three (16%) of the intervention group, and eight of the control group (42%) reporting strain ($\chi^2$= 2.047, p = 0.15).

For the group where deterioration on the FIM+FAM had occurred between discharge and six weeks, the number of items reported as distressing for carers was greater (median =5.5) than when deterioration had not occurred (median=3). However this difference was not significant.

### 7.8.1 Perceived health of carer

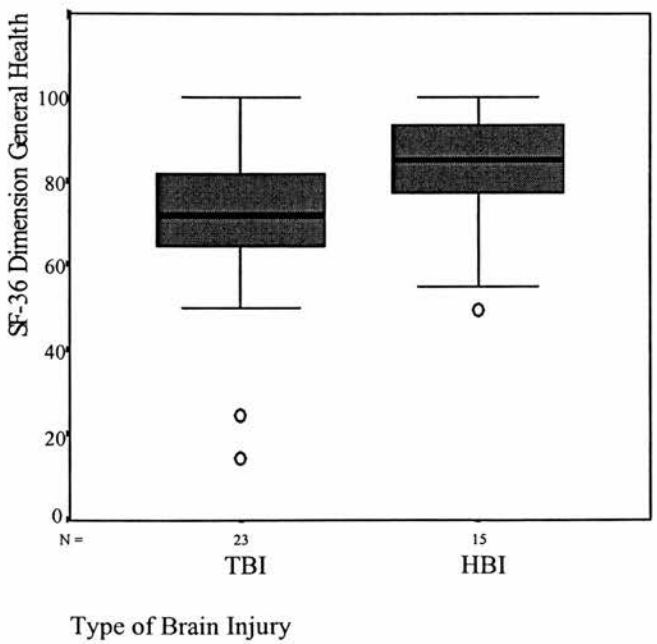
Thirty-eight carers completed a SF-36. Table 7.8-2 illustrates the scores for the intervention and control group. None of these differences were significant.

*Table 7.8-2: Perceived health of carers in Intervention and Control groups*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Condition | n | Median | 25 | 75 |
| Physical Health | Intervention | 20 | 92.50 | 71.25 | 100.00 |
| | Control | 18 | 95.00 | 77.50 | 100.00 |
| Role (Physical) | Intervention | 20 | 75.00 | 6.25 | 100.00 |
| | Control | 18 | 100.00 | 75.00 | 100.00 |
| Bodily Pain | Intervention | 20 | 91.00 | 62.50 | 100.00 |
| | Control | 18 | 100.00 | 65.75 | 100.00 |
| General Health | Intervention | 20 | 77.00 | 63.25 | 90.75 |
| | Control | 18 | 79.50 | 72.00 | 92.00 |
| Energy / Vitality | Intervention | 20 | 60.00 | 50.00 | 78.75 |
| | Control | 18 | 55.00 | 48.75 | 80.00 |
| Social Function | Intervention | 20 | 87.50 | 56.88 | 100.00 |
| | Control | 18 | 82.50 | 66.88 | 100.00 |
| Role (Emotion) | Intervention | 20 | 66.67 | 8.33 | 100.00 |
| | Control | 18 | 66.67 | .00 | 100.00 |
| Mental Health | Intervention | 20 | 74.00 | 53.00 | 87.00 |
| | Control | 18 | 72.00 | 60.00 | 80.00 |

As the first study showed no significant difference between TBI or HBI carers scores on the SF-36 (Table 5.14-8), it was briefly examined. In this study, the carers of TBI patients ranked higher on the General Health dimensions (Mann-Whitney U=104.0, p=.040) . Figure 7.8-1 shows the range of score in this dimension according to type of injury.

*Figure 7.8-1: Carer's SF-36 General Health score according to type of injury*



### 7.8.2 Services involved at six weeks after discharge

The pattern of service usage at six weeks (excluding the intervention of the outreach nurse) was similar to that of the descriptive study. The majority of patients had seen their GP (n=36, 86%) but nine patients (21%) had seen only the GP. One patient (in the control group) had not seen any professional since discharge. A further nine patients (21%) had seen five or more professionals in the six week period.

There was no clear difference in the number of professionals involved with patients in each of the conditions, although more of the intervention group were seeing in excess of five professionals (Table 7.8-3).

*Table 7.8-3: Number of professionals involved at six weeks*

| Number of Professionals | Intervention | Control | Total |
|---|---|---|---|
| 0 | | 1 | 1 |
| 1 | 4 | 5 | 9 |
| 2 | 5 | 4 | 9 |
| 3 | 4 | 9 | 13 |
| 4 | 1 | | 1 |
| 5 | 1 | 3 | 4 |
| 6 | 4 | | 4 |
| 7 | 1 | | 1 |

Given the goal of the intervention, it was unsurprising that liaison with professionals happened for all subjects in the intervention group. In the control group, contact with another professional was required in 16 cases (76%). This was usually to confirm therapy goals or to pass on relevant information to a treating therapist. In a number of cases, (n=5), liaison occurred as a result of enquiries from two separate physicians who had become aware of the project in the descriptive study phase.

As with the descriptive study, liaison rather than new referral was the most frequent cause for contact with other professionals. However, in 12 of the intervention group (57% ), referral to at least one other service was deemed appropriate with 10 (83%) people accepting referral. In the control group, it was found appropriate to refer eight people (38%) with three of the eight accepting the referral.

## 7.9 Other results of the six week assessment

### 7.9.1 Survey of satisfaction for overall study population

Two structured questions were added to the semi-structured carer interview in order to address general perceptions of how the time since discharge had progressed. The first asked carers to respond to the most applicable option concerning how many problems there had been in the time since discharge (Table 7.9-1).

*Table 7.9-1: Extent of problems in the six weeks since discharge*

| | Group | Frequency | Percent |
|---|---|---|---|
| fewer problems than expected | Intervention | 6 | 28.6 |
| | Control | 5 | 23.8 |
| about as expected | Intervention | 9 | 42.9 |
| | Control | 5 | 23.8 |
| a few more problems than expected | Intervention | 4 | 19.0 |
| | Control | 4 | 19.0 |
| many more problems than expected | Intervention | 2 | 9.5 |
| | Control | 6 | 28.6 |
| missing | Control | 1 | |

Given the small number in some of these cells, it is not possible to analyse any difference between the intervention and control groups. However, it is suggested that the first two categories indicate a sense of being prepared for the level of problems and on the other hand, the second two categories both indicate things to be worse than expected. In order to explore any difference in those who felt prepared for the problems, these two combined groups were compared (Table 7.9-2).

*Table 7.9-2: Extent of problems in the six weeks since discharge (grouped into two levels)*

| | | prepared for problems | | |
|---|---|---|---|---|
| | | no | yes | Total |
| Group | Intervention | 6 | 15 | 21 |
| | Control | 10 | 10 | 20 |
| Total | | 16 | 25 | 41 |

A chi square indicates that although there was an apparently greater level of 'preparedness' in the intervention group, this difference was not significant ($\chi^2$= 1.98, p=0.16).

The second question asked carers if they felt they had had sufficient advice or information on issues or concerns since discharge. Five carers felt that they had not required information (n=2 in the intervention group, n=3 in the control group) and one carer was not available for interview. Of the 36 carers who felt this question applied to them, a greater proportion of the intervention group expressed satisfaction with the level of information than did the controls, with this difference being significant ($\chi^2$=11.21, p=0.001).(Table 7.9-3).

*Table 7.9-3: Extent of advice or information in the six weeks since discharge*

| | not enough | enough | Total |
|---|---|---|---|
| Intervention | 2 | 17 | 19 |
| Control | 12 | 5 | 17 |

### 7.9.2 Survey of satisfaction for intervention group

In the case of the intervention group, satisfaction with the outreach nurse service was assessed by using an anonymous questionnaire as described in Chapter 6. Nineteen of the 21 carers returned the questionnaire.

All carers responded that the number of visits had been appropriate and the majority (n=13, 68%) stated that the visits were 'very helpful' with the remaining six (32%) stating they were 'quite helpful'. All but one carer (95%) stated that help was provided for all the concerns they had had in the weeks since discharge with the other stating that they had no concerns. When specifically asked how helpful the information and advice provided by the outreach nurse was, again the majority (n=18, 95%) stated it was very helpful, and the same proportion that they were very satisfied with the contact that they had had with the outreach nurse.

A wide range of comments were provided by carers in response to the open ended questions. A selection of these is provided in Appendix (xii). In summary, frequent comments were made that were concerned with the facilitation of communication with different people and services and provision of specialist information and expertise that did not seem available otherwise. Criticisms and suggestions for improvements to the service were invited but few were reported. Two people took the opportunity to express that they perceived a lack of support outside the outreach nurse service and were initially concerned about the cessation of the visits. A third critical comment was that there was a possibility of confusing the role of the professional carrying out the interventions with that of a social worker. This particular comment came from a family whose son was discharged at the time his allocated social worker was on annual leave. The final comment which indicated a criticism of the service, was from a carer whose mother was terminally ill at the time. This carer reported that although likely to be of benefit to other people, the nature of family concerns was such that the intervention was not impacting on the thing that was of most concern to her at the time.

As stated in Chapter 6, the opinion of hospital and community staff working with this patient group was sought. The questionnaire again was anonymous, other than requesting the professional background of the worker. Twenty questionnaires were sent to representatives of the therapy services the patients were using and to three voluntary organisations. Fourteen (70%) questionnaires were returned.

In response to the first question regarding whether there had been any benefits from the outreach nurse intervention, nine (64%) stated that there had been 'many' and the other five (36%) stated 'some'. The majority (n=12, 86%) stated there had been no negative effects from the intervention with two people raising the following concerns: the first being what would occur when the outreach nurse service was not available; and the second that the intervention introduced another professional into a family where a number of people were already involved. The person who made the second point, qualified it by stating that the benefits of the intervention had outweighed the negative aspect of increasing the numbers involved. A wide range of comments were also provided by professionals in

response to the open ended questions. A selection of these is provided in Appendix (xiii). In summary, community and hospital based staff frequently commented that the role was important and enhanced communication between the two. Community and support agency staff in particular, reported the benefit to themselves as well as the patient and their family in having access to specialist expertise and information.

## 7.10 Profile of function at 15 months

Of the 42 patients seen at six weeks, 35 (83%) were reassessed at 15 months after injury. Of those not seen, one had died after having a second haemorrhage. Five people did not respond to two written invitations to be reassessed. Contact with the general practitioner confirmed that in each case, the patient was alive and still at that address. One young man's father refused to allow another assessment as his son had been involved in a number of other studies and they no longer wished to be involved in research follow-up.

The majority of those who were followed up had maintained stable health since the six week assessment. Four of the intervention group (20%), had experienced a health episode requiring referral for specialist hospital treatment: one had another HBI resulting in marked cognitive and language problems; the second a lower limb amputation; the third required inpatient treatment for unstable seizures and suicidal ideation; and the fourth had diverticulitis and subsequent continence incontinence. Of the control group, three (15%) had a major health episode: one man initially treated for a TBI, had an HBI 10 months later and at the time of assessment had residual difficulties with higher language skills; the second had unstable seizures and the third had been treated for depressive illness.

It is clearly important to consider the long-term consequences of any intervention. However, it is also vital to avoid 'over interpretation' of findings given the sample size and the measures used. The analysis in this section therefore aims to determine whether any harm resulted from the intervention and thus, concentrates on selected aspects of the data.

### 7.10.1 Difference between patients followed up and those lost to follow-up

All but one of the patients lost to follow up at 15 months, were in the control group (n=5), as was the woman who died. Of the TBI group, 91% (n=21) were available for follow up, with a smaller proportion of the HBI group were available 64% (n=14).

Those who could not be followed up, tended to be older and have shorter lengths of stay in both the acute and rehabilitation unit. They were significantly less disabled at discharge than those followed up at 15 months (Mann-Whitney U=62.5, p=0.043) (Table 7.10-1).

*Table 7.10-1: Differences between those followed up and those lost to follow up*

| | | | Percentiles | |
|---|---|---|---|---|
| | | Median | 25 | 75 |
| AGE | Seen (n=35) | 37.00 | 28.00 | 58.00 |
| | Not Seen (n=7) | 58.00 | 19.00 | 69.00 |
| Post Traumatic Amnesia Severity Group | Seen (n=35) | 6.00 | 4.00 | 6.00 |
| | Not Seen (n=7) | 5.00 | 5.00 | 6.00 |
| Acute LOS | Seen (n=35) | 28.00 | 16.00 | 50.00 |
| | Not Seen (n=7) | 22.00 | 14.00 | 24.00 |
| Rehabilitation LOS | Seen (n=35) | 50.00 | 21.00 | 120.00 |
| | Not Seen (n=7) | 27.00 | 5.00 | 78.00 |
| OPCS OSS at Discharge | Seen (n=35) | 8.20 | 3.55 | 17.10 |
| | Not Seen (n=7) | 2.40 | 1.00 | 4.45 |
| OPCS at 6 weeks follow-up | Seen (n=35) | 7.50 | 2.10 | 14.55 |
| | Not Seen (n=7) | 2.60 | 1.00 | 4.70 |

The proportion of the two groups who had deteriorated at six weeks was similar. (Table 7.10-2).

*Table 7.10-2: Deterioration at six weeks according to whether followed up at 15 months*

| | | Deterioration on FIM+FAM | | |
|---|---|---|---|---|
| | | No | Yes | Total |
| Group | Seen | 16 | 19 | 35 |
| | Not Seen | 4 | 3 | 7 |

## 7.10.2 Profile of function at 15 months

The profile of function for the group appears to be slightly worse at 15 months than at six weeks after discharge (Table 7.10-3).

However, as illustrated in Table 7.10-1, those who were able to be followed up had higher levels of disability on discharge and six weeks. To that end, the total scores at six week excluding the 'lost to follow-up' group from analysis are also shown.

*Table 7.10-3: Level of function at 15 months (n=35)*

*Assessment at 15 months (n=35)*

| | | Percentiles | |
|---|---|---|---|
| | Median | 25 | 75 |
| Barthel | 20.00 | 16.00 | 20.00 |
| OPCS | 7.50 | 2.10 | 14.50 |
| FIM | 114.00 | 94.00 | 123.00 |
| FIM+FAM | 185.00 | 150.00 | 199.00 |
| ERSS | 16.00 | 7.00 | 20.00 |
| GOS | 3.00 | 3.00 | 4.00 |

*Level of function of this group at six weeks*

| | | Percentiles | |
|---|---|---|---|
| | Median | 25 | 75 |
| Barthel | 20.00 | 18.00 | 20.00 |
| OPCS | 7.95 | 1.15 | 12.25 |
| FIM | 115.00 | 101.00 | 125.00 |
| FIM+FAM | 185.00 | 161.00 | 205.00 |
| ERSS | 14.00 | 4.00 | 19.00 |
| GOS | 4.00 | 3.00 | 4.75 |

The scores at 15 months indicate a slightly improved level of function as had been found in the descriptive study.

## 7.11 Change in level of function at 15 months

As at discharge, an external rating of the FIM+FAM was used as a frame of reference for the researchers assessments of patients. In 28 cases (80%) this was the same medical researcher as at the discharge assessment. However, in four cases (11.4%) this was a different therapist, and in three cases, no external rating was available.

Table 7.11-1 illustrates that again the percentage agreement compared favourably with previous work (McPherson et al 1996). As with the six week assessment, the main researchers results have been used to compare the scores.

*Table 7.11-1: Percentage agreement between researcher and external rater at 15 months (n=32)*

| | Percentage of Ratings in Total Agreement | | Percentage with Difference > 1 Point | |
|---|---|---|---|---|
| FIM+FAM Dimension | n | % | n | % |
| Swallowing | 32 | 100.0% | | |
| Feeding | 29 | 90.6% | 1 | 3.1% |
| Grooming | 30 | 93.8% | 1 | 3.1% |
| Bathing | 30 | 93.8% | 2 | 6.3% |
| Dressing Upper | 30 | 93.8% | 1 | 3.1% |
| Dressing Lower | 31 | 96.9% | | |
| Toileting | 31 | 96.9% | | |
| Bladder | 31 | 96.9% | 1 | 3.1% |
| Bowels | 32 | 100.0% | | |
| Bed Transfers | 30 | 93.8% | | |
| Toilet Transfers | 31 | 96.9% | | |
| Bath Transfers | 28 | 87.5% | | |
| Car Transfers | 31 | 96.9% | | |
| Walking | 29 | 82.9 | | |
| Stairs | 35 | 100.0% | | |
| Comprehension | 27 | 84.4% | 1 | 3.1% |
| Expression | 28 | 87.5% | | |
| Reading | 27 | 84.4% | 1 | 3.1% |
| Writing | 27 | 84.4% | 1 | 3.1% |
| Speech Intelligibility | 29 | 90.6% | | |
| Social Interaction | 28 | 87.5% | | |
| Emotion | 22 | 68.8% | 3 | 9.3% |
| Adjustment to Limits | 28 | 87.5% | | |
| Problem Solving | 28 | 87.5% | | |
| Memory | 25 | 78.1% | | |
| Orientation | 31 | 96.9% | | |
| Attention | 26 | 81.3% | 1 | 3.1% |
| Safety Judgement | 29 | 90.6% | | |
| Employability | 26 | 81.3% | 1 | 3.1% |
| Community Mobility | 28 | 87.5% | 1 | 3.1% |

When comparing the intervention group to the controls, there was little difference between the two groups on most of the measures at 15 months. However, the median score on the ERSS indicates greater dysfunction for the controls than for the intervention group and the median score on FIM+FAM worse for the intervention group (Table 7.11-2). Given the information of Table 7.10-3, it seemed prudent to also examine the scores at six weeks excluding those lost to follow up at 15 months.

*Table 7.11-2: Level of function - intervention versus control groups (n=35)*

*Assessment at 15 months (n=35)*

| | | | Percentiles | |
|---|---|---|---|---|
| | | Median | 25 | 75 |
| Barthel | Intervention | 20.00 | 18.00 | 20.00 |
| | Control | 20.00 | 18.00 | 20.00 |
| OPCS | Intervention | 7.65 | 1.49 | 12.73 |
| | Control | 7.95 | .50 | 12.25 |
| FIM | Intervention | 115.00 | 101.00 | 124.75 |
| | Control | 117.00 | 99.00 | 126.00 |
| FIM+FAM | Intervention | 179.00 | 162.25 | 204.75 |
| | Control | 185.00 | 157.00 | 209.00 |
| ERSS | Intervention | 13.50 | 4.50 | 18.50 |
| | Control | 17.00 | 2.00 | 21.00 |
| GOS | Intervention | 4.00 | 3.00 | 4.75 |
| | Control | 4.00 | 3.00 | 5.00 |

*Level of function of this group at six weeks*

| | | | Percentiles | |
|---|---|---|---|---|
| | Group | Median | 25 | 75 |
| Barthel | Intervention | 20.00 | 16.25 | 20.00 |
| | Control | 20.00 | 15.00 | 20.00 |
| OPCS | Intervention | 7.73 | 2.41 | 13.90 |
| | Control | 6.90 | 2.00 | 17.10 |
| FIM | Intervention | 115.00 | 96.00 | 122.50 |
| | Control | 113.00 | 92.00 | 123.00 |
| FIM+FAM | Intervention | 187.00 | 151.50 | 199.25 |
| | Control | 176.00 | 138.00 | 199.00 |
| ERSS | Intervention | 14.50 | 7.25 | 19.00 |
| | Control | 16.00 | 7.00 | 22.00 |
| GOS | Intervention | 3.00 | 3.00 | 4.00 |
| | Control | 3.00 | 3.00 | 4.00 |

The median scores indicate that whilst the control group improved slightly on the FIM+FAM, the intervention group deteriorated. However, on the OPCS, the intervention group appear to have maintained their level of function whilst the control group have a slightly greater level of disability. On the ERSS, the median score for the intervention group has improved whilst for the controls it is worse. The apparent differences between the two groups were not significant. However, as the total scores provide only a limited view of the pattern of change as identified in Chapter 5, some further investigation is warranted.

### 7.11.1 Change in FIM+FAM scores

When comparing the total FIM+FAM scores, three (15%) of the intervention group and two (13%) of the control group have lower scores indicating deterioration. However, despite this similarity, the median FIM+FAM total score mentioned above, illustrated a shift towards deterioration for the intervention group as a whole in contrast to the control group. When the individual cases who deteriorated are examined, one of the intervention cases, the woman who had a second HBI which resulted in more marked cognitive and language problems, had deteriorated by 20 points in the FIM+FAM total.

Of the 35 subjects reassessed at 15 months, the majority had improved on the FIM+FAM dimension scores as shown in Table 7.11-3. When compared to the findings in the descriptive study (Table 5.10-7), the pattern of change is very similar for FIM+FAM ADL and continence items. However, a greater proportion of the intervention study population have improved in each of the other subscales.

*Table 7.11-3: Change in FIM+FAM item scores between 6wks and 15 months (n=35)*

| | (Worse) | | (Improved) | | (Same) | |
|---|---|---|---|---|---|---|
| ADL | 5 | 14% | 12 | 34% | 18 | 52% |
| Continence | 2 | 6% | 6 | 17% | 27 | 77% |
| Transfers | 4 | 12% | 14 | 40% | 17 | 48% |
| Locomotion | 1 | 3% | 23 | 66% | 11 | 33% |
| Communication | 4 | 12% | 25 | 71% | 6 | 17% |
| Psychosocial | 3 | 9% | 22 | 63% | 10 | 28% |
| Cognition | 4 | 12% | 26 | 74% | 5 | 14% |

The major difference in the pattern of results is that a greater percentage of the intervention group deteriorated on cognitive function, and of the control group in communication (Table 7.11-4).

*Table 7.11-4: Proportion of each experimental condition with lower FIM+FAM scores at 15 months*

| | Intervention (n=20) | | Control (n=15) | |
|---|---|---|---|---|
| | n | % | n | % |
| ADL | 3 | 15 | 2 | 13 |
| Continence | 1 | 5 | 1 | 7 |
| Transfers | 3 | 15 | 1 | 7 |
| Locomotion | 1 | 5 | 0 | 0 |
| Communication | 1 | 5 | 3 | 20 |
| Psychosocial | 2 | 10 | 1 | 7 |
| Cognitive | 4 | 20 | 0 | 0 |

Given the disproportionate number of the intervention group who had deteriorated in cognitive function, the characteristics of those four people were looked at. Three of the four had initially sustained an HBI and of these, two had deteriorated by one FIM+FAM point and the other by three points. The woman who had experienced the second HBI deteriorated by 3 points. For another, health in the intervening year had been poor (the woman with diverticular disease), but no such incident was reported for the remaining two. Given the small numbers, it is inappropriate to use statistical analysis to further examine this finding.

### 7.11.2 Change on OPCS scores

The majority of the study population had improved on the OPCS with 60% (n=21) having lower scores suggestive of improved function. Three of the control group (20%) and five (25%) of the intervention group had deteriorated since six weeks. However, the magnitude of deterioration is greater for the control group as a whole (Table 7-11.1 and 2). Table 7.11-5 further explores the range of deterioration on the OPCS, highlighting that for the intervention group, the changes were very small.

*Table 7.11-5: Median change on OPCS Overall Severity Score if deteriorated between six weeks and 15 months*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Group | n | Median | 25 | 75 |
| Deterioration on OPCS | Intervention | 5 | .20 | .12 | 3.38 |
| | Control | 3 | 3.00 | 2.30 | 3.00 |

### 7.11.3 Change on ERSS scores

A greater proportion of the intervention group (n=16, 80%) than the control group (n=9, 60%) had improved on the ERSS between six weeks and 15 months. As with the descriptive study, more of the sample have improved than deteriorated in each of the subscales other than Social Interaction / Isolation, and there is little difference in the proportion of each experimental condition who have improved and deteriorated (Table 7.11-6).

*Table 7.11-6: Proportion of each experimental condition with improved ERSS scores at 15 months*

| | | Intervention | | Control | |
|---|---|---|---|---|---|
| | | n | % | n | % |
| Support | Improved | 13 | 65.0% | 9 | 60.0% |
| | Same | 5 | 25.0% | 4 | 26.7% |
| | Deteriorated | 2 | 10.0% | 2 | 13.3% |
| Activity / Inactivity | Improved | 12 | 60.0% | 7 | 46.7% |
| | Same | 7 | 35.0% | 6 | 40.0% |
| | Deteriorated | 1 | 5.0% | 2 | 13.3% |
| Interaction / Isolation | Improved | 5 | 25.0% | 3 | 20.0% |
| | Same | 7 | 35.0% | 4 | 26.7% |
| | Deteriorated | 8 | 40.0% | 8 | 53.3% |
| Effect of Symptoms | Improved | 8 | 40.0% | 4 | 26.7% |
| | Same | 9 | 45.0% | 6 | 40.0% |
| | Deteriorated | 3 | 15.0% | 5 | 33.3% |

### 7.11.4 Perceived health of patients at 15 months

Thirty-two (91%) of the patients completed the SF-36 questionnaire with similar results to those of the descriptive study, with Physical Role and Vitality having the lowest median scores of the eight dimensions. The difference between the two groups at six weeks is no longer apparent (Table 7.11-7).

*Table 7.11-7: SF-36 Scores for intervention (n=19) and control groups (n=13)*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Condition | n | Median | 25 | 75 |
| Physical Health | Intervention | 19 | 60.00 | 30.00 | 85.00 |
| | Control | 13 | 80.00 | .00 | 95.00 |
| Role (Physical) | Intervention | 19 | 50.00 | .00 | 75.00 |
| | Control | 13 | 50.00 | .00 | 100.00 |
| Bodily Pain | Intervention | 19 | 100.00 | 74.00 | 100.00 |
| | Control | 13 | 94.00 | 62.00 | 100.00 |
| General Health | Intervention | 19 | 72.00 | 52.00 | 92.00 |
| | Control | 13 | 72.00 | 61.00 | 87.00 |
| Energy / Vitality | Intervention | 19 | 60.00 | 35.00 | 65.00 |
| | Control | 13 | 65.00 | 30.00 | 90.00 |
| Social Function | Intervention | 19 | 77.50 | 37.50 | 100.00 |
| | Control | 13 | 75.00 | 35.00 | 100.00 |
| Role (Emotion) | Intervention | 19 | 66.67 | 33.33 | 100.00 |
| | Control | 13 | 66.67 | .00 | 100.00 |
| Mental Health | Intervention | 19 | 76.00 | 56.00 | 84.00 |
| | Control | 13 | 64.00 | 42.00 | 86.00 |

The difference between the SF-36 scores at six weeks according to whether they were followed up at 15 months was explored and although the group who were followed up had lower ranked scores at six weeks, there were no significant differences using a Mann-Whitney U test. The change in score between six weeks and 15 months is greater for the intervention group with more positive scores, indicating improvement, for the intervention group than for the controls (Table 7.11-8)

*Table 7.11-8: Change in SF-36 score between six weeks and 15 months*

| | | | | Percentiles | |
|---|---|---|---|---|---|
| | Condition | n | Median | 25 | 75 |
| Physical Health | Intervention | 19 | 5.00 | -10.00 | 20.00 |
| | Control | 13 | -5.00 | -22.50 | 10.00 |
| Role (Physical) | Intervention | 19 | 25.00 | .00 | 50.00 |
| | Control | 13 | .00 | -50.00 | 50.00 |
| Bodily Pain | Intervention | 19 | 10.00 | 4.00 | 16.00 |
| | Control | 13 | 10.00 | 2.50 | 30.00 |
| General Health | Intervention | 19 | 10.00 | .00 | 23.00 |
| | Control | 13 | .00 | -18.50 | 11.00 |
| Energy / Vitality | Intervention | 19 | 15.00 | -10.00 | 20.00 |
| | Control | 13 | 5.00 | -17.50 | 15.00 |
| Social Function | Intervention | 19 | 12.50 | .00 | 32.50 |
| | Control | 13 | .00 | -27.50 | 30.00 |
| Role (Emotion) | Intervention | 19 | 33.33 | .00 | 33.33 |
| | Control | 13 | .00 | -50.00 | 33.33 |
| Mental Health | Intervention | 19 | 4.00 | -4.00 | 16.00 |
| | Control | 13 | -4.00 | -22.00 | 4.00 |

## 7.12 Carer perspective at 15 months

Thirty-three people completed the Relative's Questionnaire (RQ) on this occasion. As at six weeks, a greater proportion of carers in the intervention group reported behavioural disturbance, and a higher percentage of the control group reported memory problems (Table 7.12-1). The dimension score is not significantly different according to experimental condition or according to type of injury.

*Table 7.12-1: Frequency of problems on RQ reported by carers at 15 months*

| | | Intervention (n=19) | | Control (n=14) | |
|---|---|---|---|---|---|
| | | n | % | n | % |
| Intervention | Physical Symptoms | 18 | 95% | 13 | 93% |
| | Subjective Symptoms | 19 | 100% | 12 | 86% |
| | Emotional Disturbance | 17 | 89% | 9 | 64% |
| | Behaviour | 16 | 84% | 9 | 64% |
| | Language | 11 | 58% | 5 | 36% |
| | Memory | 12 | 63% | 10 | 71% |
| | Dependency | 17 | 89% | 12 | 86% |
| | Social Behaviour | 16 | 84% | 8 | 57% |

The proportion of carers reporting an increase in the number of problems on the RQ is similar between both groups as illustrated in Table 7.12-2.

*Table 7.12-2: Change in number of problems reported on the RQ between six weeks and 15 months*

| | **Number reporting more difficulties** | | | | **Number reporting fewer problems** | | | |
|---|---|---|---|---|---|---|---|---|
| | Intervention | | Control | | Intervention | | Control | |
| Physical Symptoms | 4 | 21% | 2 | 14% | 11 | 58% | 4 | 29% |
| Subjective Symptoms | 4 | 21% | 4 | 29% | 11 | 58% | 6 | 43% |
| Emotional Disturbance | 7 | 37% | 5 | 35% | 3 | 16% | 2 | 14% |
| Disturbed Behaviour | 5 | 26% | 3 | 21% | 5 | 26% | 2 | 14% |
| Language | 4 | 21% | 1 | 7% | 5 | 26% | 3 | 22% |
| Memory | 2 | 11% | 2 | 14% | 7 | 37% | 4 | 29% |
| Dependency | 4 | 21% | 1 | 7% | 9 | 47% | 6 | 43% |
| Social Behaviour | 1 | 5% | 1 | 7% | 6 | 32% | 3 | 21% |

Thirty-one carers completed the Caregiver Strain Index (89% of the sample), and again the majority reported at least one area causing distress as a result of the injury (n=28, 86%). The median number of areas reported was four as it had been at the six week assessment.

There was no difference in the total number of items reported, nor in the proportion noting specific items as distressing in relation to the experimental condition or the type of injury. Neither was there a significant difference in the number of items reported according to whether deterioration had occurred in the period from discharge to six weeks or six weeks to 15 months. However, there was a significant

difference in the number of items reported according to whether there was deterioration between six weeks and 15 months on the ERSS as there had been in the descriptive study.

*Table 7.12-3: Caregiver Strain according to deterioration in ERSS between six weeks and 15 months*

| ERSS (six weeks to 15 months) | Median Number Items | Mann-Whitney U test |
|---|---|---|
| No Deterioration (n=26) | 9 | |
| Deterioration (n=5) | 3 | 20.5, p=0.016 |

### 7.12.1 Perceived health of carer

Thirty-one carers also completed a SF-36 at 15 months. The median scores are similar between the two groups, and examination of scores according to type of injury also indicates little difference. The small sample size leads one to avoid further analysis.

*Table 7.12-4: Perceived health of carers in Intervention and Control groups*

| | Intervention or Control | n | Median | Percentiles 25 | 75 |
|---|---|---|---|---|---|
| Physical Health | Intervention | 18 | 82.50 | 63.75 | 92.50 |
| | Control | 13 | 95.00 | 42.50 | 100.00 |
| Role (Physical) | Intervention | 18 | 87.50 | .00 | 100.00 |
| | Control | 13 | 100.00 | .00 | 100.00 |
| Bodily Pain | Intervention | 18 | 77.00 | 71.00 | 90.00 |
| | Control | 13 | 84.00 | 41.00 | 90.00 |
| General Health | Intervention | 18 | 74.50 | 45.00 | 92.00 |
| | Control | 13 | 77.00 | 45.00 | 84.50 |
| Energy / Vitality | Intervention | 18 | 52.50 | 28.75 | 76.25 |
| | Control | 13 | 55.00 | 27.50 | 72.50 |
| Social Function | Intervention | 18 | 100.00 | 43.12 | 100.00 |
| | Control | 13 | 80.00 | 51.25 | 95.00 |
| Role (Emotion) | Intervention | 18 | 83.33 | 33.33 | 100.00 |
| | Control | 13 | 100.00 | 16.67 | 100.00 |
| Mental Health | Intervention | 18 | 78.00 | 61.00 | 84.00 |
| | Control | 13 | 76.00 | 54.00 | 84.00 |

## 7.13 Summary

This chapter has presented the findings of the intervention study which aimed to provide information and support to brain injured people and their families in the weeks after discharge from inpatient rehabilitation. One of the goals of this intervention was to prevent the functional deterioration after discharge from hospital found in the descriptive study.

The study population comprised 23 TBI and 19 HBI patients and their carers. When compared with the descriptive study, this sample were more severely injured, but otherwise very similar. The total of 42 subjects were divided into an intervention and control group, each of 21 subjects, by a stratification method called minimisation to keep the groups balanced in terms of important criteria. There were no statistically significant differences between the demographic characteristics of the two groups.

Functional status just prior to discharge, and six weeks after discharge was assessed using the range of measures used and evaluated in the descriptive study. In 35 of the 42 subjects, assessment at 15 months after injury was also carried out.

Although a smaller proportion of the intervention group had deteriorated on the FIM+FAM, and more had improved, no statistically significant differences to the control group were noted. However, the nature of deterioration after discharge was different to that in the descriptive study, with neither functional deficit on discharge nor length of stay being the main factors in a logistic regression model. Rather, the site of injury emerges as the only significant predictor.

The other aims of the intervention study were to determine whether an outreach nurse intervention would be perceived as useful and found to be acceptable to patients, their families and other professionals involved in their management. Both users of the service, patients and their carers, and professionals reported the outreach service had been useful and acceptable to them in terms of providing information and support, and establishing firmer links between hospital and community.

Further evaluation of the outreach nurse intervention is presented in the next chapter.

CHAPTER 8

# DISCUSSION AND CONCLUSIONS

## 8.1 Functional outcome after discharge from rehabilitation

Rehabilitation is a complex process, and as a consequence, the evaluation of rehabilitation outcomes is complex and difficult. The burgeoning literature on such outcomes is perhaps an indication of the interest in pursuing better description of the impact of rehabilitation interventions and processes.

This thesis has focussed on exploring outcome in terms of functional deficit, for those who have undergone inpatient rehabilitation following a brain injury. It is recognised that improving the level of function is only one aspect of rehabilitation interventions. However, it has been argued in Chapter 3, and elsewhere, that disability is an outcome that has frequently been poorly addressed in people with brain injury (Pentland and McPherson, 1994; McPherson et al. 1997; McPherson and Pentland, 1997[a]) and that it is of concern to both people who have had brain injuries and their families (McPherson and Pentland, 1997[b]).

This chapter discusses the results of the study in terms of whether the hypotheses have been supported or rejected, and addresses issues that have emerged throughout the course of carrying out the research.

The descriptive study aimed to explore a range of measures of function in this population and addressed two main hypotheses:

1. the level of disability will be maintained or will have improved 6 weeks after discharge
2. the level of disability will be maintained or will have improved 15 months after discharge

The main aims of the second phase of the study were to investigate whether a home based intervention, i.e. an outreach nurse intervention, had any effect on the early weeks after discharge from inpatient rehabilitation. It addressed a number of hypotheses:

1. the level of disability in the intervention group will be maintained or have improved at 6 weeks
2. any improvement will be greater for the intervention group than for controls
3. the level of satisfaction regarding information provided, will be greater in the intervention group than in the control group
4. the perceived health of the persons with brain injury and their carers will be unchanged or improved in the intervention group, whereas that of the control group will be worse
5. the service will be acceptable to patients and their families
6. the service would be acceptable to other professionals

## 8.2 The Descriptive Study

### 8.2.1 Comparison of the functional measures

The appropriateness of any measure of outcome after brain injury will vary according to the stage of recovery. In the acute or early rehabilitation period, physical disabilities are often prominent and may overshadow psychosocial issues. However, by the time the patient is discharged home, cognitive, communicative and behavioural changes may be more evident, and contribute considerably to the individual's dependence on others (Gray et al. 1994).

Perhaps the most widely used outcome measure in brain injury has been the GOS and for that reason was included in this study. As the patients had survived injury and none were in a vegetative state, the categories of the GOS applicable to the study were limited to severe disability, moderate disability and good recovery. It could therefore be argued that as the range of possibilities is exceedingly narrow, there is both a floor and a ceiling effect, and it is inevitable that the information provided is limited. The principal usefulness of the GOS in studies such as this, however, is to outline the nature of the study population. The finding that the great majority of patients had GOS scores 3 or 4, is helpful in indicating that they had persisting disability and testifies to its use as a global measure.

The Barthel, measuring as it does some basic activities of daily living, has been demonstrated to be a robust and reliable instrument at least for certain diagnostic groups. Indeed it has been recommended as the 'gold standard' of disability measures (Wade, 1992). However, if the Barthel Index were used as the sole measure of disability in this study, around two thirds of the patients would be classed as independent, while the other measures indicate persisting dysfunction in the great majority. This apparent lack of sensitivity of the Barthel Index is explicable, at least in part, by its focus on physical functions. When only the mobility or self-care components of the OPCS scale, the FIM, or FIM + FAM are considered, a sizeable proportion of the study population would also appear independent.

It is worth noting that both the GOS and the Barthel Index were devised before the introduction of the WHO definitions and classification of impairment, disability and handicap. The case has been made earlier for the usefulness of the ICIDH as a conceptual framework to measure outcome and so chart recovery. The popularity of the Barthel Index as a measure of disability may be partly explained by its widespread use, and frequent citation in the literature, prior to the introduction of a more comprehensive definition of disability.

The limited range of functions evaluated and the ceiling effect of the Barthel Index were among the reasons which stimulated the development of the alternative instruments which took account of the ICIDH (Granger et al. 1990; Fratalli, 1993). This thesis has explored the attributes of a number other measures of disability in the brain injured population, in particular the FIM and the FIM+FAM which originated in the USA, and the OPCS Scales of Disability, originating in the UK.

The FIM could be regarded as the natural successor to the Barthel, designed for widespread rehabilitation practice, irrespective of a patient's diagnosis. In recent years it has been adopted as a measure of disability, or rehabilitation outcome, in a very wide range of disabling conditions including head injury (Granger and Brownscheidle, 1995; Granger et al. 1995). The FIM continues to be used widely and is suggested by some to have superseded the Barthel Index as the gold standard of disability measurement (Granger and Brownscheidle, 1995; Ottenbacher et al. 1996). The FIM + FAM, in contrast, was designed specifically for use with brain injured patients on the precept that brain injury more commonly resulted in diverse cognitive, communicative and behavioural changes than other disorders did (Hall et al. 1993; Pentland and McPherson, 1994).

Validity and reliability data on the FIM has become increasingly available in the literature even since the start of this study (Dodds et al. 1993; Ottenbacher et al. 1996). Acceptable inter-rater reliability for most components of the FIM+FAM were established during this project, and have been published (McPherson et al. 1996). During the time this study has been running, the FIM+FAM has also been adopted increasingly by early brain injury units. It has been the object of much attention from both its proponents and critics (Barnes, 1995; Wade, 1995). However, despite this increasing attention, the FIM+FAM has had little scientific evaluation other than that which has been published by its author (Hall et al. 1996).

A major focus of this thesis has been to evaluate the FIM+FAM and, as one would expect, both positive attributes and criticisms have emerged. Positive features are that the measure is comprehensive, addressing many of the areas that are compromised after brain injury. In a survey of rehabilitation professionals who had been using the FIM+FAM, the majority reported that they found the results of the assessment informative and useful, particularly when presented as a profile of functions (Pentland and McPherson, 1994). As one goal of measurement is to facilitate a 'common language' across disciplines, this would seem a major strength.

However, in order for a measure to be an effective tool of communication, it clearly must be robust in terms of the psychometric properties. Whilst the majority of FIM+FAM items have been shown to be reliable, a number have been identified to be less so (McPherson et al. 1996). This is clearly of concern if a measure is to be used by a variety of people in different settings. The author of this thesis was a founder member of a UK-wide multi-centre working group, established to improve the definition of terminology and instructions for use of the FIM+FAM. At the time of submission of this thesis, further inter-rater studies were being carried out to ascertain whether the new definitions have improved the inter-rater reliability (Turner-Stokes, 1997 personal communication).

Another criticism of measures such as the FIM and the FIM+FAM, is that the total scores are difficult to interpret and can mask degrees of functional deficit. Given the ordinal nature of the data, merely using the total scores is inadvisable and a number of other options of how to use the scores more appropriately have been suggested in Chapter 5 and elsewhere (Pentland and McPherson, 1994).

It has been suggested that one way to explore the assessment is to review the number of items scoring '5 or less' indicating a level of help or supervision is required. A second way of looking at FIM+FAM data in this thesis has been to determine items where deterioration has occurred over time. This was of particular interest as during the course of the initial assessments, a number of families had reported that they felt things had got worse since leaving hospital. Whilst, such anecdotal reports are of interest, the researcher was keen to explore a quantitative approach to describing deterioration since discharge. Finally, whilst using total scores is inadvisable, factor analysis has supported a pragmatic approach whereby two subtotals are formed, the first by grouping the physical functioning items together, and the second by grouping communication, psychological and social functioning items.

Other researchers are investigating the use of complex mathematical procedures such as Rasch Analysis to form hierarchical scoring structures in ordinal measures of function (Fisher et al. 1995). Early results of this sort of analysis have been useful in testing how best to group items on both the FIM and the FIM+FAM together, supporting the separation of physical and cognitive functioning items and perhaps the creation of a third component, continence (Dickson and Kohler, 1996; Grimby et al. 1996; Whalley et al. 1996). However, it would seem impractical to suggest such methods should be adopted widely in the daily use of the measures given one of the goals of using these complex measures is to communicate information. Were a poll to be carried with people actually using these measures, it is suggested that one may find Rasch analysis would limit, rather than augment communication.

The high correlations between FIM and FIM + FAM scores was predictable on the basis of one instrument being derived from, and sharing many items with the other. The presentation of the two measures was done to explore whether the additional 12 items of the FIM+FAM provided valuable extra information. Although the increased information from the FIM+FAM could be regarded as modest, the detection of psychosocial difficulties is considered advantageous.

In contrast to the FIM and the FIM+FAM , the OPCS scale was devised for community survey purposes (Martin et al. 1988). The OPCS scale was, however, found by the author to compare favourably to the Barthel Index in a previous study of a mixed population of patients including stroke, but not head injury cases, attending a rehabilitation unit (McPherson et al. 1993). Others have reported similar findings in survivors of stroke reviewed after one year (Wellwood et al. 1995). Both studies showed good correlations between the two measures and that the OPCS scale was more sensitive to less severe levels of disability than the Barthel. In the present study the correlations between OPCS scale and Barthel Index were not as high as in the above reports but this probably reflects the nature of the brain injured group. The OPCS scale is relatively simple to use, and although certain of its instructions may need clarification, it has been shown to have satisfactory inter-rater reliability (McPherson et al. 1993).

In contrast to the difficulties of using the total score of the FIM and FIM+FAM, the OPCS total appears to be useful and meaningful. As highlighted in Chapter 4, the OPCS item scores are weighted and a total score calculated from the three worst scores. This study indicated that little information about the severity of an individuals' disability was lost by the calculation of the total score using this method. However, further exploration of the weightings on specific items on the OPCS might be valuable, as the original report provides little foundation for the actual weightings chosen.

The close correlation between OPCS scale and FIM provides evidence of concurrent validity of the OPCS. In terms of sensitivity in detecting disability in this population, the FIM + FAM appears to provide a modest advantage over the FIM and the OPCS, given the number at the ceiling level on each measure. However, while more of the group were at the ceiling level of the OPCS than the FIM+FAM, the proportion of the group in the mid range of the OPCS was far greater. This indicates a greater sensitivity across the range of possible scores in the OPCS measure.

Clearly further comparative studies are required, but if these confirm that the OPCS scale has similar, or perhaps improved sensitivity to the FIM and FIM+FAM and greater utility, there could be important implications for evaluating outcome in this population. It is perhaps noteworthy that a number of recent studies have similarly described the usefulness of the OPCS in neurological and mixed rehabilitation populations (Brooks et al. 1980; Wellwood et al. 1995; Brazier et al. 1996; Hunter, 1996; Rothwell et al. 1997).

The above measures were also explored in relation to how they related to the ERSS, a broader measure of medico-social dysfunction, argued in Chapter 4 to perhaps approximate handicap. Whilst the Barthel Index does not pick up disability at lower scores on the ERSS, the GOS does not discriminate at higher levels. The OPCS is the disability measure which most closely relates to the ERSS across the range of scores. One might assume from these results that disability, as measured by the OPCS, is related in a linear fashion to handicap, as measured by the ERSS. However, a logical question emerging from this finding is whether the OPCS and the ERSS are merely measuring the same thing.

This issue was addressed by examining how the ERSS score altered in relation to the score on the OPCS. Whilst 70% of the variance in ERSS score is accounted for by two OPCS dimensions (locomotor function and intellectual function), 30% cannot be explained. This highlights a number of issues. Firstly, the OPCS predicts with a fair degree of accuracy the ERSS score although other factors clearly contribute. Secondly, using measures of disability that do not address cognitive function is inappropriate in this population.

No single measure of outcome is ever likely to meet the needs of all individuals wishing to study recovery from brain injury. The specific aims of the investigator(s), the severity of initial damage, time since injury and whether the study is of people in hospital or in the community, are some of the many relevant factors. It is likely that in many instances more than one instrument will need to be

used simultaneously. In the present investigation of brain injured people after discharge from hospital, the OPCS appears to have been the most useful measure.

### 8.2.2 Functional deficit according to Type of Injury

The study has shown a great similarity in the pattern of dysfunction between the HBI and TBI groups in this study, at six weeks after discharge. There was no significant difference between the groups in the total scores for the disability measures, or, indeed, for most of the subscale scores. The statistically significant findings that the HBI patients had greater disability on the bathing and toilet transfer items of the FIM+FAM ; and that the TBI group had higher scores for the behaviour and consciousness dimensions of the OPCS scale, both have a high chance of resulting from Type I errors.

It is interesting to note that the HBI patients showed similar levels of disability to the head injured cases, confirming previously reported experience in the Scottish Brain Injury Rehabilitation Service (Soryal et al. 1992). Others have also reported comparable difficulties in the two types of brain injury (Lindberg et al. 1996; Lindberg and Fuglmeyer, 1996). However, the reported literature on the consequences of HBI tend to focus on impairments (McKenna et al. 1989[a]; McKenna et al. 1989[b]; Stenhouse et al. 1991; Hutter and Gilsbach, 1993). That which considers other outcome tends to be fairly restricted to global measures such as the GOS (Drake et al. 1988), activities of daily living (Lindberg et al. 1996) or, occasionally subjective assessments of employability (Ogden et al. 1997).

A number of methodological problems in these studies may give rise to a falsely positive view of outcome after HBI. Such problems include biased sampling whereby patients with neurological deficit have been excluded despite making up a fair proportion of the SAH population, 16% in one study (McKenna et al. 1989 [a]; McKenna et al. 1989 [b]). A particularly common methodological problem is that the period of time after injury that people have been assessed varies widely even within studies, let alone between studies. Some studies report on assessment of outcome assessed in some patients at 18 months with others in the group assessed at up to five years (Artiola i Fortuny and Prieto-Valiente, 1981). Even a very recent study which addressed perceived health in this population using the SF-36 (Deane et al. 1996), assessed some patients at six months and others up to 18 months after injury. Clearly this makes it difficult to make even broad conclusions about how the level of deficit may change with time for this group. It is perhaps unsurprising that to date, reliable figures for the prevalence of disability after SAH remain unavailable.

In this study, the functional problems for the HBI group were of a similar severity and nature as the TBI group at six weeks after discharge. By 15 months after discharge (an average of 16 to 17 months after injury) the HBI group showed more improvement than the TBI group in behavioural and social functioning but less improvement in physical functioning.

### 8.2.3 Severity of Injury

Predicting the level of deficit in terms of ability is of increasing importance in order that people are provided with the most appropriate services within a healthcare structure of limited and vigorous competition for resources. The severity ratings which have guided and improved clinical practice with

regard to care in the acute stages of recovery after brain injury have been investigated in terms of global outcome on measures such as the GOS (Jennett and Bond, 1975; Jennett et al. 1981; Timmons et al. 1987; Clifton et al. 1993; Masson et al. 1996) and cognitive impairment (Brooks and Aughton, 1979; Brooks et al. 1980; Clifton et al. 1993). There is a growing consensus that with regard to longer term outcome after traumatic brain injury, PTA is a stronger predictor than GCS. In this study, the relationship between severity of injury and functional deficit at six weeks is stronger with PTA than GCS, indicated by significant correlations for all measures except the Barthel Index.

Post Traumatic Amnesia was more strongly linked to functional deficit for the TBI group than the HBI, with a strong correlation across all severity levels. For the HBI group, the relationship between PTA and all measures except FIM+FAM Psychological Function was quite weak. This appears at least in part due to around 10% of the HBI group sustaining comparatively minor injuries but having marked levels of functional deficit. The relationship between severity of injury and functional deficit is complex and this seems particularly so for people who have experienced an HBI, relating in part to the devastating effects of secondary injury in this group (Selman and Ratcheson[a], 1997).

Whilst there would clearly be advantage in being able to accurately predict those who are likely to have persistent difficulties following injury, this study further establishes that caution must be exercised when attempting to use severity indicators for this purpose, particularly after haemorrhagic injury. In addition, the results highlight that assumptions about the relationship between severity indicators and outcome are likely to be flawed if the outcome measures are too narrow in focus.

### 8.2.4 Change in functional level after discharge

In addition to it being desirable to describe more fully, and predict the functional consequences of brain injury, it seemed a reasonable and logical next step to attempt to identify those people for whom the level of function is likely to deteriorate. This issue was explored in a detailed manner in view of the number of reports mentioned earlier of things having got 'worse since' leaving hospital. In addition, it appears to be a question that has not been explored in depth in other studies of disability after brain injury.

While the majority of patients maintained or improved in terms of overall functional status during the early weeks after leaving hospital, most deteriorated in at least one activity on the FIM+FAM, frequently in items of self-care such as dressing. A range of factors which might be predictive of deterioration were explored, and it was identified that patients with the greatest deficit on discharge, particularly in the FIM+FAM subtotal score in Psychological Function, were most likely to deteriorate.

However, a number of assumptions about how best to interpret this finding must be considered. Perhaps the most fundamental issue is whether such deterioration is of importance to the patient and/or their family; secondly, what is the most appropriate way to assess function after discharge and when should it be done; a third issue is whether such deterioration leads to any effects in the long

term. A fourth issue would be whether something might be done to prevent the apparent deterioration, but this was beyond the scope of the descriptive study.

The assessment at 15 months allowed exploration of whether deterioration was important in the longer term for either the patient or their carer. By this stage, factors such as severity of injury as indicated by PTA, relate less strongly to the level of function on most of the outcome measures. Whilst disability at six weeks after discharge is the most predictive of medico-social dysfunction on the ERSS at 15 months, the number of FIM+FAM items where deterioration has occurred early after leaving hospital is also predictive and remains so, even once the level of functional deficit at discharge is taken into account. It would appear that deterioration early in the post-discharge period has an impact on longer term levels of functioning for the person who has the sustained the injury.

In terms of the impact on the carers, the results have indicated a link between deterioration in function, and the perceived health on the SF-36 and the number of items reported as distressing on the Caregiver Strain Index. One would not state that this relationship was causative given the correlations between the disability measures and these two carer measures. Establishing causative relationships in this area is beyond the scope of this study given the nature of the measures, but the results do suggest that early deterioration is of importance in the longer term functioning of the individual and their carer.

If one accepts that measuring functional performance in this population after discharge from hospital is useful and informative, the question that must be asked is what is the best way to measure this. Clearly there are costs incurred in visiting people at home and involving members of the family in the assessment. Some recent researchers have suggested that postal or phone follow-up with such measures is a suitable and economically viable way to collect this sort of information following rehabilitation (Dombovy and Olek, 1997), even in the case of head injury (Smith et al. 1996). However, others point out that this method is perhaps less reliable in those with more severe disability as people tend to under-report problems on the telephone (Korner-Bitensky et al. 1994) and that in some sub-groups such as the elderly, it is essential to have had prior contact with the person (Worth and Tierney, 1993). Further, there is some evidence of improved compliance with assessment if it is carried out at the persons home (Brooks et al. 1984).

In this study, it appears to have been of advantage to determine the view of both the injured person, their carer, and further, to observe the person's behaviour and participation in the assessment. Certainly, it is accepted as fundamental in evaluation of psychosocial outcome after brain injury that the view of both the injured person and an informant should be sought, although a common problem in interpreting past studies is the failure of researchers to identify the source of particular pieces of information (McKinlay and Brooks, 1996). The practicalities of telephone interview or postal questionnaires make it difficult to obtain the view of both the injured person and an informant. There is clearly no opportunity to identify non-verbal cues in phone interviews or postal questionnaires and, during this study there were a number of occasions when such clues were useful indicators of areas to follow up, either with the individual or the carer.

### 8.2.5 Limits and problems of the descriptive study

In carrying out the descriptive study, a number of issues have emerged that are important considerations for interpreting this study and for future work.

During the course of this part of the study, there appeared to be a need for information and support in addition to that which was already being provided by established services. However, the nature of the study (descriptive) precluded any conclusions as to whether the provision of information and support was of help to patients and their families despite frequent reports of them being so. Recognising that such reports could not, in themselves, be considered as establishing the usefulness of such a service led to the intervention study.

The fact that while several measures were used to assess patients at follow-up, only the FIM+FAM was recorded at the time of discharge, restricted comparisons of the change in disability between discharge and home visit. Were the project to be repeated, it would be interesting to record other measures, particularly the OPCS scale, on discharge hospital to explore whether they detected function change during that period.

Most rehabilitation outcome measures, including those employed in this study, tend to be ordinal and thus open to limited statistical analysis. There have been indications that various mathematical models, such as Rasch analysis, would allow such measures to be weighted and therefore be considered as equal interval measures (Chang and Chan, 1995; Dickson and Kohler, 1996). Whilst such modelling may contribute to scale development, one doubts that it will be practical to use in the clinical setting given the sample sizes required. Further, the utility of the measures to communicate information would be far more limited.

The sample in this study were, at the time of this project, involved in a number of other research projects and as a result were being followed up by a number of different research groups. Consideration of this was made at the commencement of the study in terms of what was 'reasonable' in relation to questionnaires and when the follow-up assessment would occur. However, it may be that repeat assessments are disturbing to patients and their families and collaborative efforts between different research groups and institutions would be well-advised.

Finally, the sample are a subset of those who experience an HBI or TBI, in that they are very severely injured. This limits the applicability of the results. It would be of interest to compare a range of measures, including the OPCS Scales of Disability, in a less severely brain injured population. To date, the ceiling level of the many disability measures precludes their usefulness in the community (Hall et al. 1996).

### 8.2.6 Summary of descriptive study findings

Given the above discussion, the hypotheses are now reviewed. The first hypothesis is not supported as the majority of subjects in this sample have exhibited at least some deterioration on some measures.

There is sufficient evidence to reject the second null hypothesis as the level of function at 15 months was, in the main, improved on both the functional measures and relative's reports. However, early deterioration was found to have an effect on the level of disability and medico-social dysfunction at 15 months, and to be linked to an increased level of reported strain by carers.

Deterioration in functional level between discharge and six weeks appears to be an important factor in terms of the individual and their family.

## 8.3 The Outreach Nurse Intervention Study

Two issues emerged in the descriptive study which led to the inclusion of a trial of an intervention in the weeks after discharge from inpatient rehabilitation. The first of these was the question of whether anything could be done to prevent deterioration in functional level. The second issue was in response to the number of reports during the descriptive study that the six week assessment itself provided useful information to patients and their families.

### 8.3.1 Impact of the Outreach Nurse Service on Functional Deficit

The intervention attempted to provide patients and their relatives with information and support in the weeks immediately following discharge. The primary goals of this intervention were to promote the incorporation of strategies learned during formal rehabilitation sessions into the patients domestic situation and to facilitate the exchange of information between the users (the patient and their family), and the range of professionals they were working with including the outreach nurse. The hypothesis was that facilitation of those skills and adaptive strategies would result in improved functional level.

More of the intervention group than controls improved (and fewer deteriorated) on both the FIM+FAM and the ERSS although the difference falls short of significance. Further, the intervention fell just short of significance as being a predictor of deterioration with the site of injury being the most predictive variable.

The assumption that might follow from these findings is that the intervention had no significant impact on maintaining function in the weeks after discharge. However, the results summarised above, raise some important issues. The allocation of subjects to each experimental condition was balanced on many criteria, but not discharge functional level and the intervention group tended towards greater functional deficit on discharge. On the basis of the descriptive study, one might predict that the intervention group would show evidence of more deterioration than the controls due to the greater functional deficit, but this did not occur. Rather, the controls tended towards more deterioration. It is also interesting that whilst the site of injury was not a predictor of deterioration in the descriptive study, it became so in the intervention study. Caution in interpreting which site of injury was most likely to bring about deterioration is necessary given the small numbers for some injuries and the pragmatic approach to identifying the major injury in those with multiple insult. However, the results indicate a trend for those with frontal and diffuse injuries to show the greatest deterioration, irrespective of whether they received the intervention. These injuries have been identified elsewhere

as being those likely to cause most problems in the long-term (Newcombe, 1993; Gennarelli et al. 1982).

As functional deficit on discharge was the strongest predictor of deterioration in the descriptive study and not for the intervention study, the implication is that something has ameliorated its impact. However, on the evidence in this study, one cannot say with confidence that the intervention is the factor which has brought about the change. It may be that with more balance between the groups on discharge functional level, particularly in terms of behaviour and cognitive function, the intervention would have demonstrated a statistically significant impact rather than one approaching accepted levels of significance. Secondly, an increased sample size would have made it possible to determine a clearer picture of the effect of the intervention.

This highlights that statistical analysis has limited power in studies based on small samples. The risk is that one might discard a meaningful result simply because not enough subjects were recruited, a Type II error. There are a number of alternatives, other than the obvious one of increasing sample size, that can be done to increase the power of the tests. Most frequently, the significance of a finding is based on a two-tailed test where no assumptions are made about the direction of the results. An example of this in the present study would be assuming that the intervention could impact on patients by either increasing deterioration OR reducing it. In this case, one would clearly test both ends of the known distribution to find out if the result lies outside it and is therefore meaningfully different, beyond the risk of chance. A one-tailed test doubles the chance of finding a significant result as one predicts the direction of change. For example, in this study, one might predict that the likelihood of the intervention making peoples' level of function worse is so slim, that it is acceptable to ignore one end of the distribution, only looking for a significant finding at the other end. Indeed, a one tailed test was used in Section 7.7.1 on the basis that deterioration occurred more often in the control group. However, the result was not significant.

It is very common practice to use very tight inclusion and exclusion criteria in order to optimise the chance of finding a significant result. For instance, many studies exclude subjects with alcohol or drug histories or only include those who were employed at the time of the injury. This is a way of attempting to make the population as homogeneous as possible, thereby increasing the sensitivity of the measures to describe the sample and keeping the standard deviation of the distribution low despite a small sample. From the results of this study, one might suggest that replicating the study, excluding those with frontal or diffuse injuries, may show the intervention to have a significant impact. This is a purely hypothetical notion given the ethical issues involved and that studies using such tight criteria are arguably of less value as they do not relate to the real life situation.

One point of view is that clinical research fails to adequately recognise, and discuss the fact that a non-significant findings in small samples is likely to result from a Type II error. Ottenbacher (1995) suggests that failure to address this issue:

> '.. can reduce the sensitivity of experimental procedures, and produce quantitative results that do not accurately reflect the impact of treatment.'

The solution is clearly to establish the power of the test prior to carrying out the study (Altman, 1982). Although this is increasingly done, it remains a difficulty in rehabilitation research, particularly where the sample size under investigation tends to be small and heterogeneous. Altman also points out that for a dichotomous variable, (for example presence or absence of deterioration) rather than a continuous variable, sample sizes in the order of n=1600 are required to detect a reduction in group membership from 15% to 10% with 90% power at $p<0.05$.

It has been suggested that research, such as the Outreach Nurse Intervention Study, which does not have the power to achieve statistical significant results should not take place (Altman 1982). Other, more pragmatic, approaches would advocate the importance of distinguishing between statistical and clinical significance (Ottenbacher, 1995). That is, addressing the non-significant result in the light of the probability of it being a Type II error.

A further point of interest that emerged in the intervention study, is that at six weeks the relatives of those in the intervention study, reported greater problems since the injury in areas such as emotional disturbance and social behaviour. Whilst this may relate in part to the greater level of disability that the intervention group recorded in parallel domains on the functional measures, it is important to consider the possibility that the intervention caused harm in any way. It may be that discussing areas of concern and providing information over the preceding weeks has heightened the relatives awareness of existing problems. There is no evidence that carers in the intervention group are detrimentally affected in terms of perceived health or distress at either six weeks or 15 months, and whilst this is reassuring, the small sample makes it unwise to draw major conclusions. The issue of concern is that practitioners sometimes assume that more information is by definition, better information although research is particularly inconsistent in this regard (Teasdale, 1993). It appears that obtaining the correct balance between not enough information on the one hand, and too much on the other is somewhat dependent on responding to that which caregivers wish to know and the way the information is given (Miller and Mangan, 1983; Teasdale, 1993).

This study responded to the areas in which patients and their families had indicated they wanted further information during the descriptive study. The intervention was also influenced by comments such as 'you just don't know the questions to ask'. The prompt list based on problems and questions in the pilot group, was used to ensure that specific areas that may be of concern but not volunteered were covered. Work in other areas has suggested that in order for the information to be accepted without raising anxiety, it is vital that the practitioner is sensitive to the level of depth appropriate at any one time and for any one family (Grahn and Danielson, 1996; Slevin et al. 1996). Further, it has been suggested that initiating contact with information resources is infrequent despite persistent difficulties after discharge (Bostrom et al. 1996). This study attempted to address whether this service was delivered at a level appropriate to the needs of the families by the questionnaire on their perceptions of the intervention. Whilst the majority of carers indicated that the service was delivered in a sensitive manner, some of the feedback raises an issue worth further consideration.

Clearly, how people in families adapt after brain injury is a complex phenomenon, and is beyond the scope of this particular thesis. However, comments in the satisfaction questionnaire and the Caregiver Stain Index illustrate that the injured person is just one component of the process of adapting. At the same time as families are having to adjust to what is a major health crisis, there are coexisting demands on the carer in terms of other commitments. Indeed there are factors such as their own personality type, that of the injured person, pre-existing family structures and external problems which all have a part to play on both the difficulties and the adaptive strategies they may utilise (Oddy et al. 1978 [b]; Novack et al. 1991; Kosciulek et al. 1993; Hall et al. 1994; Kosciulek, 1994; Leach et al. 1994; Mitchley et al. 1996). Whilst this intervention had as its primary focus the person with the injury, the intervention attempted to be sensitive to the nature of inter- and extra-personal issues for both the individual and their carer.

### 8.3.2 Perceived benefits of Outreach Nurse Intervention to patients and carers

Any intervention must be evaluated in terms of what it actually achieves, but it may be that what users perceive it to achieve is also of importance. This seems particularly relevant in a population such as that in this study where voluntary organisations as well as professionals have often reported a lack of support for families in the weeks after leaving hospital (Frank, 1994; Seed, 1994; Hubert, 1995).

Keeping in mind the problems of measuring 'satisfaction' discussed earlier, the view of patients and carers on the period after discharge was explored. The group who received the outreach nurse service reported significantly greater satisfaction with the level of information provided in the weeks after leaving hospital, and the results also indicate that this group felt more prepared for the problems that cropped up. The overall view of the service emerging from the anonymous questionnaire was that the service was acceptable and provided information and support at a level required and understood for both the patient as well as that of the carer. Given the limited information one gets from tightly structured questionnaires, there was an effort to include a qualitative approach as well as questions that could be dealt with statistically. Comments were actively sought that criticised the service as well as seeking to find out what was received most positively. Carers particularly reported appreciating the link to the specialist unit through the outreach nurse, both in terms of the expertise and information that allowed, and also the transfer of communication that this facilitated between the various parties involved. Patients reported a feeling of being spoken to 'at their level' rather than 'as a child' or at a level they could not understand. Although comments were actively sought criticising the service, the majority of qualitative feedback was positive. It is clearly important to interpret such findings within the limits of the small sample size and that people are unwilling to criticise services (Mahon, 1996).

### 8.3.3 Sustained effects of the intervention study

In order to see if the effects of the intervention study were sustained, patients and their families were reviewed 15 months after injury. Although the follow-up rate at 15 months is high (83%), the diminished sample size, particularly in the control group, makes it difficult to determine significant effects on the pattern of change in functional level according to the experimental condition. However,

it seems reasonable to conclude that the intervention did not lead to harm and that the intervention group did not deteriorate to any greater extent than the control group in the year after the intervention.

This raises a question about what one might expect in the way of longer term effects of such an intervention. This particular project was directed at attempting to maintain or improve the level of function in the weeks after discharge. As such, it may be considered naïve to expect widespread effects, in a comparatively short time frame, for this group of people whose lives have fundamentally been altered in such a major way. Nevertheless, this appears to be what other recent studies have expected in terms of what they have set out to achieve and what they have used as outcome measures (Greenwood et al. 1994; Dennis et al. 1997).

Such a mismatch between the goal of the intervention and the outcomes measured, will result in the intervention being judged as a failure, on the basis of not meeting a target that was unrealistic in the first place. For instance, a number of brief and broadly based interventions have been described as disappointing because they have not ameliorated anxiety and depression, or failed to enhance variables such as 'well-being' (Forster and Young, 1996; Dennis et al. 1997). However, it can hardly be considered surprising that an intervention is found wanting when it was not specifically directed at influencing this type of outcome. Whilst some workers acknowledge the limits of their methodology in this regard, (Dennis et al. 1997) others do not and make the conclusion that the intervention has not had any effect (Forster and Young, 1996).

One aspect of this is that there must be a clear understanding of the processes and outcomes which are the object of an intervention. To anticipate that a 'side-effect' of an intervention which primarily aims to provide information and support would be to reduce depression, ignores the major determinants of depressive illness. What seems more appropriate is that one must consider whether the precise goal of an intervention has been achieved and if so, what are the costs incurred. Thus, researchers may be best to hypothesise that a useful intervention is one that achieves its specific goal whilst having no detrimental effects on variables such as depression, perceived health and so on in the short to medium term.

With hindsight, the fourth hypothesis in this thesis seems inappropriate, and it would be far more appropriate to hypothesise that there would be no difference in carers perceived health on the basis of the intervention.

### 8.3.4 Perceived benefits of Outreach Nurse intervention to other professionals

Whilst it is relatively common for studies to address the level of satisfaction in different professional groupings, this tends to be in terms of how the professionals interpret their own roles rather than that of how they perceive the introduction of change (Peruzzi et al. 1995). A number of recent studies have explored the perceptions of health workers to changes in service delivery and how their level of satisfaction has been affected (Goode, 1995; Reda, 1995). It was decided in this study to focus more explicitly on how other professionals perceived the introduction of this service in terms of its impact

on the patient and their family, as well as determining perceived benefits or problems for the professionals own management of the patient.

This was an interesting area to consider given the possibility that the outreach nurse role might be seen as encroaching on the roles of others, such as the social worker or community occupational therapist. A further risk identified by the researcher was that other colleagues may have seen the role as creating a heavy demand for their services. However, the majority of people completing the questionnaire reported that they felt there were benefits for the patients and their family, in addition to feeling that their own management of the patient was assisted rather than harmed. As with the feedback from the patient and their family, there is clearly the possibility that staff would under-report criticisms in their desire to be supportive.

Of those studies done to evaluate other workers' perspectives of a service, the majority have focused on specific treatments for specific conditions, and have sought the view of one particular profession, for instance a group of medical practitioners or nurses (Boghossian et al. 1996; Wiles and Lindsay, 1996; Brown et al. 1997). The recent studies of interventions with people with neurological disabilities such as stroke or head injury (Greenwood et al. 1994; Forster and Young, 1996, Dennis et al. 1997, Wade et al. 1997) have not addressed this particular outcome so it is not possible to determine whether this service has been any more acceptable to other professionals than another model of service might have been.

The introduction of an outreach service in this study did not compete with other existing services for funding, being entirely supported from a research grant. It is possible that the views of other professionals might have been less favourable had the post been perceived as having been created in preference to another development or at the cost of shifting funds from an existing resource. To some degree this concern may be ill-founded as the hospital management has supported the establishment of an outreach nurse subsequent to the completion of the research. Although not yet fully evaluated, other workers in the field continue to utilise the service and express their appreciation and acceptance of the service provided.

One possibility is that this type of service could be incorporated into the existing work of people such as health visitors and community occupational therapists. Certainly, prior to analysing the data obtained in the study, it was something the researcher considered might be appropriate. However, feedback from both the users of the service and other professionals highlights two key factors being fundamental to the service being perceived as useful. The first was the expertise of the worker and the access her involvement provided to other specialist knowledge when needed; and secondly, the personal characteristics of the worker involved. As discussed in Chapter 6, the attributes of the person carrying out an intervention have long been recognised as vital (Beck, 1994; Calnan et al. 1994; Biegel et al. 1995), and there is no reason to doubt that most effective generic workers have the personal characteristics required to establish positive relationships with clients. However, the realistic scenario is that, those staff already working in the community do not have access to sufficient numbers of patients with moderate to severe brain injury in order to feel confident of being up to date

with the knowledge and skills required. In the months since the completion of the intervention study, many conversations have taken place with colleagues in the community who have reported the value of having someone attached to a specialist brain injury unit as a link to services and knowledge. However, it clearly is essential for specialist services to work in conjunction with community colleagues, and where possible and appropriate, the decision making should be locally based.

### 8.3.5 Limits and problems of the intervention study

Whilst the intervention study has advanced the understanding of how a clearly directed intervention may be structured and how it may impact on a population such as this, there are a number of limitations that it is prudent to highlight.

In view of the incidence of brain injury, and the proportion of patients referred for rehabilitation, it was anticipated that the study sample would be small. This is a recognised limit to other studies (Forster and Young, 1996). In this study, a comprehensive summary of findings has been presented such that the clinical significance of the study can be interpreted. However, whilst the small sample clearly reduces the power of the intervention to produce statistically significant results, the results approach statistical significance and the clinically significant effects of the intervention have been described and discussed. Further, the caseload of comparable workers is around twenty patients and therefore, whilst it is a limit of the study, it is realistic given the situation.

Clearly one way to address the problem of lack of power is to establish multi-centre studies (Greenwood et al. 1994). In this way a larger sample is recruited and the probability of a Type II error minimised. However, despite getting around some of the methodological problems of rehabilitation research, other problems may come to the fore. For example, the particular study mentioned above has been widely criticised on the basis of inadequate methodological rigour in other ways, such as the randomisation procedure, lack of definition of intervention, lack of focus on outcome measurement chosen and so on. Further, whilst larger samples increase the power of the study in brain injury outcomes, researchers have reported that the sample is so heterogeneous, that drawing meaningful conclusions remains difficult (Dennis et al. 1997; Wade et al. 1997).

Whilst an attempt was made to have an 'impartial' assessment of the patients, it is recognised that the absence of this at six weeks (other than in terms of the self-report questionnaires), is a major weakness of the study's methodology. This should be rectified in further studies. At the time that the study was planned, a pragmatic approach was taken which in hindsight would have been better avoided.

An allied point to this is that although the researcher was blind to subjects on allocation to the experimental conditions, it would have been wise to have an external person co-ordinate allocation of patients to each group. This would also allow a future study to consider the discharge functional level as one of the criteria in the stratification of the sample.

There is much criticism that research in disablement focuses too much on issues that patients and their relatives do not consider to be important. On one hand, there is little doubt that there would be

acceptance of the information and support component of the intervention based on studies mentioned previously. However, it is wise to question whether the focus of the intervention on maintenance of functional performance is warranted. The descriptive study highlighted that a number of the concerns raised by patients and carers in the weeks after discharge related to the facts that their relative was bored, and was in need of help for activities such as remembering things or people. Patients particularly focused on the residual disability in areas such as their mobility. As a result, it seems justifiable that the level of functional deficit is of importance in the early period after discharge. There is some suggestion that self-esteem is a vital component in adaptation after head injury (Prigatano, 1991) with it being a major factor in longer term outcomes such as employment and family issues. A hypothesis that one might wish to test is whether enabling patients and their relatives to see improvement in their level of function in the early post discharge period, would raise self esteem and therefore lead to longer term benefits in relation to outcomes such as return to work, quality of life or perceived health. As argued in this chapter, such outcomes are not amenable to measurement in the short or medium term and to that end, a follow up study at periods such as five and ten years would be extremely valuable.

The question of whether it is ethical for one group of patients to be provided with a treatment and another not to be, is a difficult one in rehabilitation. This is particularly so as there appears an underlying assumption that rehabilitation treatments can only do good as they have common-sense appeal, and therefore excluding people from the intervention is unethical.

However, any intervention can cause harm and it is therefore arguable that any intervention study must have a control group in order to validate it as a treatment strategy. It is possible to get around this problem by cross-over designs if time is a variable of little consequence. However, clearly when one is wishing to carry out a study concerning a particular time period, this is not an option. In considering the ethical issues of this study, much discussion took place and as stated earlier, ethical approval was obtained. A number of aspects appeared to justify the decision to have a control group, in addition to the importance of time as of primary concern in this study. All those in the control group were provided with the same service that the descriptive study sample group had been given over preceding months. That is, all reasonable and relevant information was provided at the six week assessment with referral and consultation with other workers. Secondly, it was hoped that a small study would provide enough information, with little risk to patients as to whether the service did in fact provide valuable outcomes. Further, all those recruited were informed that the study was to explore whether such visits were of benefit to them and they were given the opportunity for the information and support without entering the study.

However, it is likely that studies of such interventions will remain contentious. Indeed, a recent comment in the British Medical Journal, was highly critical of a study looking at supporting stroke patients and their families after discharge on the basis of providing limited information about the study (McLean, 1997). This criticism could also be made of this study and whilst the viewpoint is

respected, the researcher would maintain that it is justifiable given the above discussion. However, consideration of such ethical questions is vital when considering carrying out intervention studies.

Although there was no discussion with any other professional about which patients were receiving the intervention, and the consultants for patients in both groups were provided with the results of the assessment, there is clearly the risk that the presence of the outreach nurse might have affected treatment by other professionals. Knowledge of the objectives of the study may have had an effect on treatment of patients in the control group, thereby minimising the effect of the intervention. Indeed, the researcher was approached by colleagues both within the hospital and the community, on a number of occasions in order to discuss difficulties with patients outwith the intervention group. This has been recognised as a problem in other recently published studies (Forster and Young, 1996) and some have attempted to ameliorate this effect by specific randomisation procedures in multicentre studies as mentioned earlier. However, in this study, the risk of affecting behaviour of other professionals was accepted as a potentially confounding variable.

The study did not address the GP's views of the service. To some degree, this was influenced by the nature of the intervention leading to more contacts with paramedical colleagues, voluntary organisations and hospital based medical services. Information was passed on to the GP, either directly by the outreach nurse if indicated, or indirectly when a letter at the time of review by the consultant was routinely sent. In retrospect, it would have been useful to survey the GP's view of the service and this is being addressed in the service now running as a consequence of the study.

### 8.3.6 Summary of intervention study findings

The power of the intervention study is clearly compromised by a number of factors, as discussed above. In light of this, one is cautious in interpreting the results. However, a number of issues about the nature of problems after discharge from inpatient rehabilitation which emerged in the descriptive study have been more fully addressed in the intervention study. The findings are summarised in terms of the hypotheses postulated at the beginning of the study.

1. The level of function has been maintained or improved in the majority of the intervention group in contrast to that of the control group. However, there is insufficient evidence on which to reject the first null hypothesis.

2. Given that the major predictor of deterioration has changed from being the level of disability itself, the intervention has clearly impacted on the way functional level changes between discharge and six weeks. However, the intervention itself falls below an acceptable level of significance, with the site of injury being the major predictor. It appears that those people whose major injury is diffuse (in the case of TBI) or frontal in either HBI or TBI are the most likely to deteriorate. Thus there is insufficient evidence on which to reject the second null hypothesis.

3. A significantly greater proportion of the intervention group report they have received enough information leading to rejection of the third null hypothesis. The hypothesis that the intervention group will express greater satisfaction with information is supported.

4. In hindsight, the fourth hypothesis is inappropriate, and it is of little surprise that it is rejected.
5. The evidence leads to reject the null hypothesis that the service will not be acceptable to patients and their families. The hypothesis that the service has been acceptable to patients and their families is supported.
6. Finally, the evidence is that the service was acceptable to professionals and indeed other agencies involved in the care of this group. The null hypothesis is rejected and the hypothesis that intervention was acceptable to professionals supported.

### 8.3.7 Recent developments in disablement terminology

In July 1997, the World Health Organisation proposed a new model of disablement, called ICIDH -2 which is now available for consultation (Üstün, 1997). Although the original WHO model has contributed a great deal to the development of systematic investigation into the functional consequences of illness and injury, it has also been widely criticised. In response to criticisms, and to ongoing developments in health and social policy, ICIDH-2 has been put forward.

The new version builds on the framework of the previous ICIDH models, with three levels grouped under an umbrella term, 'disablement'. These three levels are *Impairment, Activity and Participation,* with WHO claiming that the terms are fully operationalised. As a consequence, it is suggested that the ICIDH-2 will provide more useful tools of assessment than ICIDH-1, improving the description of the functional consequences of ill-health. At the same time, the claim is that the terms are less stigmatising than 'disability' and 'handicap'. The definitions appear similar to those of ICIDH-1 with *Activity,* the term used in place of disability, defined as being:

> 'the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.'

The purpose of the new model also sounds similar to the original, in that it aims to:

> 'provide a unified and standard language to serve as a frame of reference for the consequences of health conditions.'

It is clearly too early to say how ICIDH-2 might influence the development of measures in 'disablement', and, whether it will firmly establish a common language in disablement. Given that a another of its aims is to 'synthesise' medical and social models of disablement, it seems possible that the ICIDH-2 has the potential to be either challenging and productive, or to remain simply a focus for discussion.

## 8.4 Conclusions

How best to obtain the most favourable outcomes for patients after brain injury, and to demonstrate that they are favourable, continues to be a major concern for all involved in rehabilitation whether they are users of service, providers, or indeed purchasers. Without having measures that address the main difficulties that this population experience, services are likely to remain underfunded and misdirected. Secondly, without exposing rehabilitation interventions to rigorous and appropriate evaluation, we will continue to be in doubt as to which management strategies should be adopted and

which rejected. The contribution that the work of this thesis has made is best considered in relation to these two components.

The descriptive study has evaluated a number of measures of function in a group of people with brain injury. It has, therefore, contributed to a better understanding of those measures, and also the nature of disability in people with traumatic head injury and haemorrhagic brain injury and its impact on the carers. A number of papers have been published in connection with this work and the author has contributed to developments within the field of outcome assessment in brain injury. Given the rise in the number of measures that have emerged, even during the course of this project, there appears to be a need for a database of robust measures that have been extensively tested for their psychometric properties and their utility. Until this occurs, clinicians will continue to find themselves confronted by a plethora of measures, being unsure as to which is the most suitable for their purposes. On the basis of this study, it appears appropriate to recommend the further use of the OPCS Scales of Disability in measurement of functional level in a population with brain injury.

The second part of the study has illustrated that a comparatively short intervention may impact on the nature of deterioration in function after brain injury rehabilitation. Further, the intervention has been shown to be acceptable to both patients and their families, and other workers.

It is difficult to make a recommendation about how to proceed with exploring the most beneficial way to assist patients and their families after rehabilitation. It would seem expeditious to mount mutlicentre comparative studies of both natural recovery and interventions. In addition, it seems there is a need to build on the longitudinal work which has been done, in an attempt to understand more comprehensively the possible link between deterioration and long-term consequences in terms of the impact on the individual and their family. Finally, it has been suggested elsewhere that:

> 'Rehabilitation services that will restore optimal function, do not result from the general application of standard formulae, but, rather, depend upon precise evaluation of functional assets and impairments and precise prescriptions based on knowledge' (Kottke and Lehmann, 1990)

It seems perhaps more fitting to suggest that in contrast to 'precise prescriptions', rehabilitation is needing precise knowledge and flexible prescriptions. This study has attempted to extend the body of knowledge regarding the functional consequences of brain injury, and to explore a model of intervention based on that knowledge.

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# An inter-rater reliability study of the Functional Assessment Measure (FIM + FAM)

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**Keywords** Functional Assessment Measure, brain injury.

**Summary**

There is an increasing demand for measures of outcome to evaluate the effects of rehabilitation interventions for brain injury from clinicians, research workers and healthcare providers and purchasers. The Functional Assessment Measure (FIM + FAM), an expanded derivative of the Functional Independence Measure (FIM), is designed specifically for this purpose for this patient group. This study examined the inter-rater reliability of the FIM + FAM between two independent raters, a physician and a nurse, the subjects being 30 in-patients in a neurological rehabilitation unit. The results show that the inter-rater reliability was good (kappa values 0·50 to 0·95) for all but one of the 30 items rated on the FIM + FAM. The exception (with a kappa value of 0·35) was 'adjustment to limits'. Higher agreement was found for rating of physical activities than for cognitive, communication and behavioural items.

## Introduction

There is increasing recognition of the need to demonstrate and evaluate the effects of rehabilitation interventions for clinical, academic and financial reasons.[1–3] Both providers and purchasers of health care face decisions regarding what aspects of rehabilitation outcome to measure, what measures are the most appropriate to use, and also when and how to apply them. It is generally agreed that one of the primary goals of rehabilitation is the restoration of functional capabilities. Thus, measures of functional performance are frequently advocated as desired outcome instruments in rehabilitation.[4–6] A number of such measures are now in widespread use in the USA, UK and Australia,[1,4,5] in particular the Functional Independence Measure (FIM).[7] The FIM was developed by a national task force of clinical, research and administrative experts in rehabilitation as an instrument for general use by all professional disciplines in rehabilitation practice.[7] It was designed to address a broader range of activities and provide a wider scoring range than earlier disability measures, which tended to focus on a restricted number of activities of daily living. It consists of 18 items rated on a seven-level ordinal scale and is described as being a minimal data set. An expanded derivative of the FIM, the Functional Assessment Measure (FAM), was developed to address the specific problems of brain-injured patients.[6,8] Thus, it contains an additional 12 items which give greater emphasis to cognitive, communicative and psychosocial function. The recently accepted custom is to use the abbreviation FIM + FAM for the complete 30-item Functional Assessment Measure.[8]

While validity and reliability data on the FIM are increasingly available in published literature,[9–14] such information with respect to the FIM + FAM is scant.[2,6] We describe an inter-rater reliability study of the FIM + FAM in an inpatient neurological rehabilitation unit.

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## Method

### THE FUNCTIONAL ASSESSMENT MEASURE (FIM + FAM)

The 30 items which comprise the FIM + FAM are listed in Table 1, with individual FIM and FAM components identified as such. The seven-level ordinal scoring scale is also summarized in Table 1. Manuals describing the scoring procedures for both the FIM and the FAM are available from the respective authors (addresses provided in the Acknowledgements). In addition to plain text versions, decision tree format manuals are available. Prior to commencing the study, information on best practice was sought from the developers of the FIM + FAM and the decision tree format manual was used as the principal reference.

### RATERS

There are different options for training available from both the FIM and FAM centres. Video-recordings of case material are available for the FIM, whereas the FAM centre provides a series of case studies (vignettes)

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Table 1 Dimensions and scoring of FIM + FAM

(a) *Dimensions*†

| *Self-care* | *Mobility* | *Communication* | *Cognitive function* | *Psychosocial* |
|---|---|---|---|---|
| *Swallowing* | **Transfers** | Comprehension | Problem-solving | Social interaction |
| Feeding | Bed/chair | Expression | Memory | *Emotion* |
| Grooming | Toilet | *Reading* | *Orientation* | *Adjustment to limits* |
| Bathing | Bath | *Writing* | *Attention* | *Employability* |
| Dress-upper | *Car transfers* | *Speech intelligibility* | *Safety judgement* | |
| Dress-lower | | | | |
| Toileting | **Locomotion** | | | |
| Bladder | Walk/wheel | | | |
| Bowel | Stairs | | | |
| | *Community* | | | |

(b) *Scoring of levels of function*

| | |
|---|---|
| *Independent (no helper)* | 7 Complete independence |
| | 6 Modified independence |
| *Dependent (helper)* | 5 Supervision or set-up |
| | 4 Minimal contact assistance |
| | 3 Moderate assistance |
| | 2 Maximal assistance |
| | 1 Total assistance |

† FAM items in italics.

for practice application. Both raters had experience working in the neurological rehabilitation unit but were not involved in the clinical care of the patients at the time of the study. Rater 1, a physician, had not used the FIM + FAM while Rater 2, a registered nurse, had 2 years experience in the use of the FIM + FAM. Both, however, underwent training with the FIM video-recordings and FAM vignettes. In addition, a pilot study group of five patients were assessed, and ratings discussed to identify any common scoring difficulties.

### PATIENTS

Over a 3-week period in July/August 1994, 30 inpatients of the neurological rehabilitation service were included in the study. The majority of patients ($n = 21$, 70%) were receiving rehabilitation following brain injury. Thirteen (43%) of these patients had sustained a traumatic brain injury (TBI) and eight (27%) had experienced haemorrhagic brain injury (HBI). Four patients (13%) were receiving rehabilitation following spinal surgery and five patients (17%) had other neurological conditions (two Guillain-Barré syndrome, one Parkinson's disease, one neuropathy of unknown aetiology and one multiple sclerosis). The patients had a mean age of 48·4 years with a range of 17–88 years.

### ASSESSMENT PROCEDURE

Each patient was assessed on the same day by the two independent raters. Neither rater had prior detailed knowledge of the individual, nor were they involved in their routine care. Assessment was based on observation of the patient in the ward environment, with both raters observing the patient at the same time periods, throughout the morning and afternoon ward routine. Other information was gained by patient interview, and interview with the main carer, in this case the patient's primary nurse – both raters again being present. Further details, as required, were obtained from the therapists treating the patient. Each assessment took approximately 1–1½ hours. Raters recorded their scores separately, storing their data with an independent party. Results were not discussed until after the 3-week study period was complete.

### DATA ANALYSIS

There is much discussion in the literature about the most appropriate method of analysis of data in order to evaluate inter-rater reliability.[9,15] The following tests were used in this study. First, it is useful to identify the proportion of scores where there is total agreement, and also to examine the difference between two raters. With discrete scores the magnitude of the observer differences are presented more informatively as means and approximate confidence intervals[16] rather than medians, nearly all of which are zero. However, in view of the ordinal nature of the data, significance testing for observer differences is more appropriately based on the Wilcoxon matched-pairs signed-rank test. For this

eason both confidence intervals and the Wilcoxon test re shown. Finally, unweighted kappa statistics were sed to evaluate the relationship between raters as pposed to the more commonly quoted correlation oefficients. Correlation coefficients, such as Pearson's or pearman's, show only the degree of association, while ne unweighted kappa statistic defines the degree of bsolute agreement.

The data was analysed on SPSS for Windows with the xception of the calculation of some kappa statistics. rograms were written within SAS for this, and results hecked against the values in SPSS where available.

## Results

The FIM + FAM scores for each item ranged from 1 o 7, and the mean, median and standard deviation for ach item, by each rater, are presented in Table 2. This shows that the central tendency of the ratings, particularly in the physical dimensions, are towards the higher scores, indicative of greater independence in the activities. No patient was found to be at the ceiling level in all items by either rater.

Table 3 summarizes the percentage of ratings where there was total agreement between the two raters for each dimension. Also shown is the percentage of ratings where the difference between scores was greater than one point on the FIM + FAM scale. For only one item, Adjustment to Limits, was the percentage agreement less than 60%, although for six others, less than 70% were in complete agreement. The mean differences between raters and 95% confidence intervals are also shown in the table. The confidence intervals highlight possible observer bias in four items, with the significance of these differences shown on the Wilcoxon test as follows, where $z$ is the test statistic: Employability $z = -2{\cdot}52$ ($p = 0{\cdot}01$),

**able 2** FIM + FAM scores for raters 1 and 2 ($n = 30$)

| | *Rater 1 (doctor)* | | | *Rater 2 (nurse)* | | |
|---|---|---|---|---|---|---|
| *)imension*† | *Mean* | *Median* | (*SD*) | *Mean* | *Median* | (*SD*) |
| **DL** | | | | | | |
| *wallowing* | 6·33 | 7 | (1·52) | 6·30 | 7 | (1·62) |
| eeding | 5·83 | 6 | (1·49) | 5·77 | 6 | (1·57) |
| Grooming | 5·47 | 6·5 | (1·85) | 5·50 | 7 | (1·87) |
| athing | 5·03 | 5 | (1·97) | 5·00 | 5 | (2·12) |
| Dressing (upper) | 5·47 | 6 | (1·85) | 5·50 | 6 | (1·89) |
| Dressing (lower) | 4·90 | 6 | (2·14) | 4·90 | 6 | (2·12) |
| oileting | 5·07 | 6 | (2·16) | 5·13 | 6 | (2·16) |
| ladder | 5·43 | 7 | (2·16) | 5·47 | 7 | (2·15) |
| owel care | 6·00 | 7 | (1·84) | 6·07 | 7 | (1·86) |
| **lobility** | | | | | | |
| ed transfers | 5·20 | 6 | (1·95) | 5·13 | 6 | (2·03) |
| oilet transfers | 5·30 | 6 | (1·90) | 5·20 | 6 | (1·97) |
| ath transfers | 4·50 | 4·5 | (2·08) | 4·43 | 4·5 | (2·05) |
| *Car transfers* | 3·50 | 2 | (2·75) | 3·57 | 2 | (2·78) |
| Valking/wheelchair | 5·47 | 6 | (1·87) | 5·40 | 6 | (1·94) |
| tairs | 3·13 | 1 | (2·52) | 3·20 | 1·5 | (2·47) |
| *Community mobility* | 4·20 | 5 | (2·37) | 3·90 | 4·5 | (2·41) |
| **Communication** | | | | | | |
| Comprehension | 5·93 | 7 | (1·60) | 5·77 | 6·5 | (1·63) |
| Expression | 5·77 | 7 | (1·83) | 5·70 | 7 | (2·04) |
| *Reading* | 5·50 | 6 | (1·85) | 5·67 | 6 | (1·79) |
| *Writing* | 4·87 | 5·5 | (2·06) | 5·33 | 6 | (2·02) |
| *Speech intelligibility* | 6·33 | 7 | (1·15) | 6·40 | 7 | (1·19) |
| **Psychosocial** | | | | | | |
| ocial interaction | 5·77 | 7 | (1·77) | 5·83 | 7 | (1·68) |
| *Emotion* | 5·00 | 6 | (1·60) | 5·23 | 6 | (1·63) |
| *Adjustment to limits* | 4·93 | 5·5 | (1·96) | 5·10 | 6 | (2·12) |
| *Employability* | 4·10 | 4 | (1·88) | 3·73 | 4 | (1·57) |
| **Cognition** | | | | | | |
| Problem solving | 5·07 | 6 | (2·10) | 4·77 | 5·5 | (2·37) |
| Memory | 4·97 | 5·5 | (2·22) | 4·97 | 6 | (2·22) |
| *Orientation* | 5·33 | 6 | (2·02) | 5·50 | 6 | (1·93) |
| *Attention* | 5·10 | 6 | (2·20) | 5·13 | 6 | (2·22) |
| *Safety judgement* | 4·80 | 5 | (1·97) | 4·70 | 5 | (2·02) |

† FAM items in italics.

Table 3 Percentage of ratings with total agreement with mean difference and confidence intervals for difference ($n = 30$)

| Dimension† | Percentage of ratings in total agreement | Percentage with a difference of > 1 FAM point | Difference between raters | | 95% confidence intervals for mean difference (rater 1–rater 2) |
|---|---|---|---|---|---|
| | | | Mean | (SD) | |
| **ADL** | | | | | |
| *Swallowing* | 96·7 | 0 | 0·03 | (0·18) | −0·03 to 0·10 |
| Feeding | 93·3 | 0 | 0·07 | (0·25) | −0·03 to 0·16 |
| Grooming | 90·0 | 0 | 0·01 | (0·31) | −0·15 to 0·09 |
| Bathing | 86·7 | 0 | 0·17 | (0·46) | −0·15 to 0·25 |
| Dressing (upper) | 93·3 | 0 | 0·10 | (0·40) | −0·18 to 0·12 |
| Dressing (lower) | 86·7 | 3·3 | 0·20 | (0·48) | −0·20 to 0·20 |
| Toileting | 86·7 | 0 | 0·13 | (0·35) | −0·20 to 0·07 |
| Bladder | 96·7 | 0 | 0·03 | (0·18) | −0·10 to 0·03 |
| Bowel care | 80·0 | 3·3 | 0·20 | (0·48) | −0·26 to 0·13 |
| **Mobility** | | | | | |
| Bed transfers | 83·3 | 3·3 | 0·20 | (0·41) | −0·10 to 0·23 |
| Toilet transfers | 90·0 | 0 | 0·10 | (0·31) | −0·01 to 0·21 |
| Bath transfers | 86·7 | 0 | 0·13 | (0·35) | −0·07 to 0·20 |
| *Car transfers* | 83·3 | 0 | 0·20 | (0·48) | −0·26 to 0·13 |
| Walking/wheelchair | 83·3 | 3·3 | 0·13 | (0·35) | −0·07 to 0·20 |
| Stairs | 93·3 | 3·3 | 0·07 | (0·25) | −0·16 to 0·03 |
| *Community mobility* | 66·7 | 10 | 0·57 | (0·97) | −0·11 to 0·71 |
| **Communication** | | | | | |
| Comprehension | 83·3 | 3·3 | 0·17 | (0·38) | 0·03 to 0·31 |
| Expression | 73·3 | 6·7 | 0·33 | (0·61) | −0·19 to 0·32 |
| *Reading* | 76·7 | 0 | 0·23 | (0·43) | −0·34 to 0·01 |
| *Writing* | 73·3 | 10 | 0·53 | (0·94) | −0·83 to −0·10 |
| *Speech intelligibility* | 63·3 | 10 | 0·27 | (0·45) | −0·26 to 0·13 |
| **Psychosocial** | | | | | |
| Social interaction | 63·3 | 6·7 | 0·33 | (0·55) | −0·31 to 0·17 |
| *Emotion* | 70·0 | 3·3 | 0·43 | (0·68) | −0·52 to 0·06 |
| *Adjustment to limits* | 46·7 | 10 | 0·63 | (0·67) | −0·51 to 0·17 |
| *Employability* | 73·3 | 0 | 0·37 | (0·67) | 0·12 to 0·62 |
| **Cognition** | | | | | |
| Problem solving | 60·0 | 3·3 | 0·43 | (0·57) | 0·06 to 0·54 |
| Memory | 86·7 | 0 | 0·13 | (0·35) | −0·14 to 0·14 |
| *Orientation* | 63·3 | 6·7 | 0·43 | (0·63) | −0·45 to 0·11 |
| *Attention* | 80·0 | 0 | 0·23 | (0·50) | −0·24 to 0·17 |
| *Safety judgement* | 66·7 | 10 | 0·43 | (0·63) | −0·18 to 0·38 |

† FAM items in italics.

Writing $z = -2{\cdot}40$ ($p = 0{\cdot}01$), Comprehension $z = -2{\cdot}02$ ($p = 0{\cdot}04$) and Problem Solving $z = -2{\cdot}02$ ($p = 0{\cdot}04$).

With the exception of the item Adjustment to Limits, all have kappa values $\geqslant 0{\cdot}5$, and for 14 of the 30 items the values are $\geqslant 0{\cdot}75$. The higher kappa values occurred in items predominantly within the ADL and mobility sections of the scale. Individual kappa values (and standard errors) are shown in Table 4 ranked in ascending order.

The seven items with less than 70% total agreement between the two raters correspond, as one would anticipate, to those with the lowest kappa values. These are Adjustment to Limits, Problem Solving, Speech Intelligibility, Orientation, Community Mobility and Safety Judgement. Two of these items, Problem Solving and Social Interaction, are FIM as opposed to FAM items.

## Discussion

The results reported in this study indicate a satisfactory inter-rater agreement for all but one of the 30 FIM + FAM items, namely Adjustment to Limits. There is some controversy as to the level of agreement associated with different kappa values, and a degree of subjectivity is accepted in interpretation.[17] While some have suggested that values greater than 0·2 represent fair agreement,[18] we took the more conservative value of 0·4 or over, to indicate fair to good agreement.[19] Even with these stricter criteria, only one dimension failed to reach a level of fair agreement. We highlighted in the results section the other six dimensions which had the poorest levels of agreement between raters in both percentage agreement and kappa scores. However, the above criteria indicate that they have satisfactory inter-rater reliability

**Table 4** Kappa values for individual items ($n = 30$)

| *Dimension*† | *Kappa* | *Standard error* |
|---|---|---|
| *Adjustment to limits* | 0·35 | 0·10 |
| Problem solving | 0·50 | 0·10 |
| *Speech intelligibility* | 0·51 | 0·12 |
| *Orientation* | 0·51 | 0·10 |
| Social interaction | 0·53 | 0·12 |
| *Community mobility* | 0·55 | 0·10 |
| *Safety judgement* | 0·55 | 0·10 |
| *Emotion* | 0·56 | 0·11 |
| *Writing* | 0·58 | 0·10 |
| Expression | 0·60 | 0·11 |
| *Employability* | 0·67 | 0·10 |
| *Reading* | 0·68 | 0·10 |
| Bowel care | 0·69 | 0·12 |
| *Attention* | 0·73 | 0·09 |
| Bed transfers | 0·74 | 0·09 |
| *Car transfers* | 0·74 | 0·09 |
| Comprehension | 0·75 | 0·10 |
| Dressing (lower) | 0·79 | 0·08 |
| Walking/wheelchair | 0·80 | 0·11 |
| Bathing | 0·82 | 0·08 |
| Toileting | 0·82 | 0·08 |
| Memory | 0·83 | 0·08 |
| Bath transfers | 0·83 | 0·07 |
| Grooming | 0·85 | 0·08 |
| Toilet transfers | 0·87 | 0·07 |
| Stairs | 0·90 | 0·07 |
| Feeding | 0·90 | 0·07 |
| Dressing (upper) | 0·91 | 0·06 |
| *Swallowing* | 0·92 | 0·08 |
| Bladder | 0·95 | 0·05 |

† FAM items in italics.

in this population. These items, with the exception of Community Mobility, all come from the Communication, Psychosocial and Cognitive Function subscales of the FIM + FAM. This concurs with our previous experience with other raters, who found these dimensions the most difficult to score.[3]

There are no published inter-rater studies of the Functional Assessment Measure (FIM + FAM).[20] However, a number of reports,[9–14] albeit not specifically with brain-injured people, have described the reliability of the Functional Independence Measure (FIM). Although there has been wide variation in the methodology used, there is a degree of consensus that the instrument is reliable, and this is indeed the case in this present study.

As with the FIM + FAM, the FIM itself is described in grouped activities (as in Table 1) with the exception that the headings Psychosocial and Cognitive Function are merged under the title Social Cognition. Irrespective of the statistical methodology employed, several authors have demonstrated good agreement between individual raters for the 13 items which come under the headings of Self-care and Mobility.[9–11,21,22] Thus, Brousseau,[11] describing the evaluation of multiple sclerosis patients by two physiotherapists, reported kappa values of greater than 0·4 for all items except locomotion by walking or wheelchair. Others have also noted poorer levels of agreement for this item within the Self-care and Mobility categories.[21] However, in this particular study a kappa value of 0·8 was reached. In another recent study the 13 Self-care and Mobility items of the FIM were found to be more valid than, and equally reliable in the assessment of disability as, the Barthel ADL Index.[14]

The Communication category of the FIM comprises the two items Comprehension and Expression, and both attained satisfactory levels of agreement in the present study and that of Hamilton *et al.*[9] Some authors have reported rather poorer reliability for Expression,[11,21,22] including one study with spinal cord trauma patients.[22] However, the spinal cord patient group in our study, and others, tend to have high scores, or minimal disability in this domain. The lack of agreement suggested in these studies appears to be more an artefact of the analyses used, in that another test such as a weighted kappa may be a more appropriate test to use where there is little variability in the range of scores attained.[22,23]

The category with which most authors note poorer agreeement between raters is Social Cognition. This includes the two FIM items Problem Solving and Social Interaction (with the poorest levels of agreement in the present study), the remaining item being Memory. While Hamilton *et al.*[9] reported no difficulty with these items, a number of others have commented on difficulties with them, although most describe them as reaching satisfactory levels of reliability.[11,21,22] Both raters in this study experienced more difficulty in rating patients on items in the psychosocial and cognitive domains. Such subjective difficulties in this and other studies[3,21] may in part highlight factors contributing to the poorer levels of agreement found. Segal *et al.*[22] suggest that there are broadly two sources of variation in item ratings likely to produce lower levels of inter-rater agreement. The first of these is that an individual item in a scale can be poorly constructed in that it is inadequately defined or does not relate well to the underlying conceptual basis of the scale, leading to a systematic error in rating. Secondly, raters may use the scale systematically, but differently to one another, due to inadequate understanding of scale items. In some FAM items, including Adjustment to Limits, raters are required to assess the impact of the patient's difficulty on 'general life functioning'. However, there is no clear exposition of the meaning of this phrase, allowing different interpretations to be applied. In addition, the instructions for some items in the FIM + FAM require that the assessor makes subjective judgements about factors contributing to the patient's

level of function. Thus, in the item Safety Judgement, two different factors effect the score attained. Firstly, the ability to make 'decisions' about safe activities, and secondly the extent to which one is 'physically capable' of being safe. Additional guidance in the manual could assist the assessor to weigh different aspects consistently.

In four items on the FIM+FAM, possible observer bias is highlighted by significant Wilcoxon results. The items in which this was found to be the case are Comprehension, Problem Solving, Employment and Writing. In Comprehension, Problem Solving and Employment, Rater 2 (the more experienced rater) allocated lower scores than Rater 1. The FIM+FAM manual advises raters to award the lower of two scores if in some doubt as to which level to assign. Discussion between the two raters, at completion of the study, considered that one factor contributing to these differences was that Rater 2 more rigorously applied this principle. This illustrates one of the reasons for poor inter-rater reliability suggested by Segal *et al.*[22] previously, that of inadequate understanding of a scale. It is important that any rules of application of a scale are explicit, and it may be that the FIM+FAM manual should contain repeated mention of such advice for raters.

It is perhaps not surprising that physical activities, such as the Self-care and Mobility items of these instruments, are in general easier to rate and more reliably scored than assessments of observable behaviour in communicative and psychosocial domains.[3] However, in a brain-injured population it is these areas which have long been recognized as of most importance in terms of subsequent handicap.[24] The additional 12 FAM items are designed to address these particular problems in patients with brain injury. As one might expect, therefore, FAM items comprise the great majority of those dimensions with kappa values of less than 0·75. We would suggest that, with the possible exception of Adjustment to Limits, the FAM forms a useful and reliable expansion of the FIM for this population. It is important that adequate training is provided, and the decision tree manual is suggested as the primary assessment source.

It is salutary to note that, in the past, many measures have been routinely used for many years without basic psychometric testing, a case in point being the Barthel ADL Index,[25] which remained untested for inter-rater reliability for over 20 years, despite its widespread use in clinical practice.[26–28] There is clearly a need for further reliability studies of both the FIM and the FIM+FAM. In addition, clarification of assessment instructions for some dimensions may be beneficial. In this way ease of use would be improved, and potential benefits to inter-rater reliability could be measured. However, this study provides evidence that, at present, all but one item in the FIM+FAM (Adjustment to Limits) has satisfactory inter-rater reliability.

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# Disability in patients following traumatic brain injury – which measure?

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Head injury results in a wide range of functional sequelae. Thus, measuring solely physical aspects of functioning may fail to highlight the actual level of disability. This study compares a commonly used measure of physical disability, the Barthel Index, with three recently devised measures – the OPCS Scales of Disability, the Functional Independence Measure (FIM) and Functional Assessment Measure (FIM + FAM). Fifty-four head-injured subjects were assessed following discharge from an in-patient rehabilitation unit utilizing each measure. The majority of subjects had no detectable disability according to the Barthel Index. In contrast, only four subjects (7%) attained maximal scores for independence with the OPCS scale; two (4%) with the FIM and only one subject (2%) with the FIM + FAM. This reflected the nature of the disabilities in activities such as intellectual functioning, communication, behaviour and wider aspects of mobility measured by the OPCS, FIM and FIM + FAM but not in the Barthel Index. The relationship between all measures was significant (Spearman ranked correlations $P < 0.001$) but correlations were greater between OPCS, FIM and FIM + FAM than with the Barthel. The results of this study would support considering the use of scales other than the Barthel Index when describing disability following traumatic head injury.

**Zur Frage der Messung von Fähigkeitsstörung bei Patienten nach Schädelhirntrauma**

Mit einer Kopfverletzung sind vielfältige funktionale Folgeerscheinungen verbunden, so daß die Messung ausschließlich physischer Aspekte des Leistungsvermögens häufig das tatsächliche Ausmaß der Fähigkeitsstörung ("disability") nicht abzubilden vermag. Die vorliegende Untersuchung vergleicht den Barthel-Index als ein gängiges Verfahren zur Messung physischer Fähigkeitsstörung mit drei neueren Instrumentarien: den OPCS Disability Scales, dem Funktionalen Selbständigkeitsindex (FIM – Functional Independence Measure) und dem Functional Assessment Measure (FIM + FAM). Nach Entlassung aus einer stationären Rehabilitationsabteilung wurden 54 schädelhirnverletzte Probanden mit allen vier Assessmentinstrumenten beurteilt. Mit dem Barthel-Index wurde bei der Mehrzahl der Patienten keine Fähigkeitsstörung festgestellt. Im Gegensatz dazu erreichten in der OPCS-Skala nur 4 Personen (7%) die maximalen Selbständigkeits-Scores, im FIM 2 (4%) und im FIM + FAM nur 1 Person (2%). Dies spiegelte die Art der festgestellten Fähigkeitsstörungen in Bereichen wie intellektuelles Leistungsvermögen, Kommunikation, Verhalten und Mobilität im weiteren Sinn wider, die mit OPCS, FIM und FIM + FAM, nicht aber mit dem Barthel-Index gemessen werden können. Die Korrelationen zwischen den Instrumenten waren signifikant (Spearmansche Rangkorrelationen $p < 0.001$), lagen jedoch zwischen OPCS, FIM und FIM + FAM höher als mit dem Barthel-Index. Die Ergebnisse der Untersuchung sprechen dafür, für eine Beschreibung von Fähigkeitsstörungen nach Schädelhirntrauma den Einsatz dieser anderen Skalen dem des Barthel-Index vorzuziehen.

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**Incapacites chez les traumatises craniens: quelles mesures?**

Le traumatisme crânien débouche sur une importante variété de séquelles fonctionnelles. C'est la raison pour laquelle, mesurer uniquement les aspects physiques comporte le risque de ne pas mettre en lumière la réalité actuelle de la situation de handicap. Cette étude compare l'Index de Barthel qui est habituellemet utilisé pour évaluer le handicap physique avec trois instruments de mesure récemment mis au point: – l'Echell d'Incapacités OPCS, la Mesure de l'Indépendance Fonctionnelle FIM et l'Evaluation des Mesures Fonctionnelles (FIM + FAM). 54 personnes traumatisées crâniennes ont été évaluées après leur sortie d'un centre de rééducation par chacun de ces instruments. La majorité des sujets ne présentaient pas d'indices visibles à l'Index de Barthel. Par contre, seulemet quatre patients (7%) atteignaient le score maximum à l'Echelle OPCS, deux (4%) à celle de FIM et un seul (2%) lorsqu'on utilisait FIM + FAM. Ceci montre bien la nature des incapacités survenant dans des activités mettant en jeu le fonctionnement intellectuel, la communication, le comportemnt et d'autres aspects de mobilité que mesurent l'OPCS, le FIM et le FIM + FAM ce que ne fait pas l'Index de Barthel. Les relations entre ces mesures sont significatives (Spearman: $p < 0.001$) mais les corrélations étaient plus importantes entre OPCS, FIM et FIM + FAM qu'avec l'Index de Barthel. Les résultats de cette étude tendraient à prouver que l'usage d'échelles autres que l'Index de Barthel est recommandé pour décrire les incapacités des traumatisés crâniens.

**La discapacidad en los pacientes de una lesión cerebral traumática – ¿Cómo medirla?**

Las lesiones craneanas ocasionan un amplio abanico de secuelas funcionales. Además, la pura medida de los aspectos fisicos del funcionamiento puede ser insuficiente para esclarecer el nivel real de discapacidad. El presente estudio compara un instrumento de medición comunmente utilizado, el índice de Barthel, con tres instrumentos de medición recientemente concebidos: la Escala de Discapacidad OPCS, la Medida de Independencia Funcional (MIF) y la Medida de Valoración Funcional (MIF + MVF). Cincuenta y cuatro sujetos con lesión craneal fueron valorados conforme a cada uno de estos instrumentos de medida después de ser dados de alta de una unidad interna de rehabilitación. Según el indice de Barthel la mayoria de los sujetos no tenían una discapacidad perceptible. Como contraste, sólo cuatro sujetos (7%) alcanzaban las punctuaciones máximas de independencía según la escala OPCS; dos (4%) con la MIF y sólo un sujeto (2%) con la MIF + MVF. Esto reflejaba la naturaleza de las discapacidades en actividades como el funcionamiento intelectual, la comunicación, la conducta y los aspectos más amplios de la movilidad que se miden con la OPCS, la MIF y la MIF + MVF pero no con el Barthel. Los resultados de este estudio aconsejarían el uso de otras escalas diferentes del índice de Barthel para describir la discapacidad resultante de los traumatismos craneanos.

**Keywords:** disability, measurement, head injury

## Introduction

It is now accepted that measurement of the functional consequences of trauma, and any subsequent recovery, is part of good practice in rehabilitation. Such measures tend to concentrate on disability, defined in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) as 'the extent to which a person is unable to perform an activity in a manner or at a rate which is considered normal for that population' (World Health Organization, 1980). Although the ICIDH report is clear that factors such as psychological disturbance may contribute to reduced functional ability, the assessment of disability has, until recently, been dominated by measures that look almost exclusively at physical aspects of functional activities. Trauma to the brain results in disabilities of both mental and physical elements with psychological factors often the most important in the

long term (Jennett and Bond, 1975; Jennett *et al.*, 1981; Gray *et al.*, 1994). Nevertheless, there remains a tendency to use measures of purely physical disability to characterize the head-injured population and decide eligibility for rehabilitation services (Frattali, 1993). The Barthel Index (Mahoney and Barthel, 1965), is probably the most widely used activities of daily living measure and has been shown to be robust and reliable (Roy *et al.*, 1988). Indeed it has been promoted as the 'gold standard' of disability measures, against which all others should be compared (Wade, 1992). However, its restricted focus, insensitivity in detecting change and low ceiling effect limit its usefulness in rehabilitation practice (Applegate, *et al.*, 1990, Granger *et al.*, 1990).

As a result of such criticisms, and in a climate where the need to measure the outcome of rehabilitation programmes is increasingly recognized, a number of other measures of disability have been developed. The aim of this study was to compare three such measures of rehabilitation outcome with the Barthel Index in a population of head-injured patients shortly after discharge from in-patient rehabilitation. The measures chosen for this study were the Disability Scale from the Office of Population, Censuses and Surveys (OPCS) (Martin *et al.*, 1988), the Functional Independence Measure (FIM) (Granger *et al.*, 1986) and the Functional Assessment Measure (FIM + FAM) (Hall, 1992).

## Methods

### MEASURES

The outcome measures differ both in the range of items covered, and in the method of scoring employed. A brief outline of each measure follows and Table 1 provides a summary of the component items of each scale and its scoring method. For each of the disability measures, it is possible to identify subscales of mobility and self-care items, as indicated in Table 1.

*The Barthel Index (Mahoney and Barthel, 1965).*

This scores the patient's level of dependence in ten activities of daily living (ADL) commonly disturbed in those with physical disabilities. The original scoring was in five-point increments from 0–100 but it is now the convention to rate each item from 0 (dependent) to 2 or 3 (independent) with total possible score ranging from 0 to 20, with higher scores indicating greater independence (Wade, 1992).

*The Office of Population, Censuses and Survey's (OPCS) Disability Scale (Martin* et al., *1988)*

The OPCS was devised and validated for surveying the prevalence of disability in populations. However, it has been shown to be useful in a clinical setting (McPherson *et al.*, 1993; Wellwood *et al.*, 1995). It assesses 13 functional areas and individual items are scored from 0 to a maximum of 12.5 according to the subject's ability to perform the function. In contrast to the Barthel Index, higher scores correspond to greater levels of disability or reduced independence.

*The Functional Independence Measure (FIM) (Granger et al.*, 1986)

The FIM was devised by a national taskforce of clinical, research and administrative experts in rehabilitation in the United States of America as an instrument for general use

in rehabilitation practice. It was originally developed to measure 18 core areas of function at four levels of dependence, and as such, to be a 'minimum data set'. It has since been validated in a seven-level score format (Hamilton *et al.*, 1991; Chau *et al.*, 1994) and is now widely used internationally (Hamilton *et al.*, 1987; Hall *et al.*, 1993). For each item, a score of 1 indicates complete dependence on others to achieve the activity and a score of 7 represents complete independence.

*The Functional Assessment Measure (FIM + FAM) (Hall, 1992)*

This was developed as an expanded version of the FIM specifically for use with brain-injured patients by the addition of 12 items (FAM) to the 18 items of the FIM (Hall, 1992; Pentland and McPherson, 1994). The additional 12 items, which constitute the FAM component, cover a greater range of cognitive and psycho-social functions. Thus, the complete FIM + FAM comprises 30 items with the same scoring format as the FIM.

SUBJECTS

The sample consisted of head-injured patients from the Scottish Brain Injury Rehabilitation Service, Edinburgh, discharged consecutively over a 15-month period (October 1992–December 1993). They were included in the sample if they consented to a post-discharge visit and lived within approximately one hour's travelling distance of Edinburgh. There were no refusals. The resulting sample of 54 patients were visited at home, 4–6 weeks after discharge from in-patient rehabilitation.

**Table 1.** Summary of the principal features of outcome measures

| *Measure* | *Items assessed* | *Scoring method* |
|---|---|---|
| Barthel Index | feeding*, grooming*, bowels*, bladder*, dressing*, toilet use*, bathing*, transfers†, walking†, stairs† | Individual item scores (0–2 or 3). Total disability score (0–20) where the lower the score the greater the level of disability |
| The OPCS Scale | locomotion†, reaching and stretching, dexterity, personal care*, continence*, seeing, hearing, communication, behaviour, intellectual functioning, consciousness, eating, drinking and digestion, disfigurement | Individual item score (0–12.5). Total overall severity score (0–21.4) is calculated from the three worst item scores and may be grouped into ten severity levels. The higher the score the greater the level of disability. |
| The FIM | feeding*, grooming*, bathing*, dress–upper*, dress–lower*, toileting*, bladder*, bowel*, bed/chair transfers†, toilet transfers† and bath transfers†, walking/wheelchair†, stairs†, comprehension, expression, social interaction, problem solving, memory | Individual item score (1–7) based on degree of assistance (help, supervision, aids required or safety concern). The lower the score the greater the level of disability. |
| The FAM (only to be used in conjunction with the FIM) | swallowing*, car transfers†, community mobility†, reading, writing, speech intelligibility, emotion, adjustment to limits, employment ability, orientation, attention, safety judgement | As for FIM |

*Self-care items; †Mobility items.

**Table 2.** Patient data ($n$ = 54)

| | *Age (in years)* | *GCS* on admission to acute unit* | *PTA *(in days)* | *Length of stay in acute hospital (days)* | *Length of stay in rehabilitation unit (days)* |
|---|---|---|---|---|---|
| Mean | 36 | 7.7 | 35.5 | 33.1 | 46.8 |
| Median | 31 | 6 | 21 | 28 | 24.5 |
| Range | 14–75 | 3–15 | 1–150 | 12–78 | 4–385 |

*Glasgow Coma Scores available in 48 of the 54 cases.

The majority (41 or 76% ) of the subjects were male. The cause of injury was road traffic accidents in 32 (59%) of the 54 cases, with 23 patients being vehicle occupants, seven pedestrians and two bicyclists. Sixteen others (30%) sustained their injuries as a result of falls and the other six (11%) were assaulted.

Nineteen (35%) subjects required surgical intervention for subdural, extradural or traumatic subarachnoid haemorrhage, and 12 (22%) had contusion or haemorrhage not requiring surgery. The remaining 23 (43%) had sustained a diffuse injury with no discrete haemorrhage. Other details are summarized in Table 2, which demonstrate that the majority of subjects had experienced moderate or severe closed head injury requiring prolonged hospital management.

#### PROCEDURE

All assessments were carried out by one of the authors (K McP), a registered nurse with previous experience using the measurement instruments. In each case, the assessment took place in the patient's home with another person nominated by the patient (usually a relative) present. Each assessment took approximately one to two hours and consisted of observation of activities complemented by interview data from both the patient and relative.

#### STATISTICS

Spearman rank order correlation coefficients were calculated using SPSS for Windows, comparing each disability measure: Barthel Index, OPCS, FIM and FIM + FAM.

## Results

### *Sensitivity of disability measures*

The median score for each of the four disability scales are presented in Table 3 and the proportions who were assessed as being at the highest possible level of function for each scale are given in Table 4. Both tables show the total scores and the mobility and self-care subscale scores. The median Barthel total and subscale scores were at the best level possible and 69% of patients had total scores of 20, indicating independence in all the activities covered by the Barthel Index.

The locomotion and personal care median scores for the OPCS also register at the highest level of function. However, the median total score is 6.85, or level three for the ten possible severity categories, indicating that dimensions other than mobility or self-care

**Table 3.** Median scores of scales ($n$ = 54)

| | *Total score* | | | *Mobility* | | | *Self care/ADL* | | |
|---|---|---|---|---|---|---|---|---|---|
| | *Median* | *IQR** | *Best possible* | *Median* | *IQR* | *Best possible* | *Median* | *IQR* | *Best possible* |
| Barthel Index | 20 | 1 | 20 | 8 | 0 | 8 | 12 | 1 | 12 |
| OPCS Scale | 6.85 | 6.26 | 0 | 0 | 3 | 0 | 0 | 1 | 0 |
| FIM | 117 | 10.25 | 126 | 34 | 3.25 | 35 | 56 | 4 | 56 |
| FIM + FAM | 189 | 24.5 | 210 | 46 | 6.25 | 49 | 63 | 4 | 63 |

IQR*, interquartile range.

**Table 4.** Proportion of patients ($n$ = 54) assessed at highest level of function on each measure

| | *Total n (%)* | *Mobility n (%)* | *Self-care n (%)* |
|---|---|---|---|
| Barthel Index | 37 (69) | 45 (83) | 38 (74) |
| OPCS | 4 (7) | 30 (56) | 34 (63) |
| FIM | 2 (4) | 24 (44) | 33 (61) |
| FIM+FAM | 1 (2) | 11 (20) | 33 (61) |

activities are associated with disability in the study group. Indeed only four (7%) of the subjects would be rated as without disability from their total OPCS score. The OPCS Overall Severity Score (OSS) is made up of the three highest (worst) scores an individual achieves. It is interesting to note that those items most frequently scored as 'worst', are intellectual function, locomotion (mobility), behaviour and communication.

The median self-care subscale of both FIM and FIM + FAM are also at the highest level of function and 61% of the study population attained the highest possible score for this subscale with both measures. The median FIM mobility score is one lower than the possible maximum and the FAM mobility subscore is down three points from the maximum possible. Less than half the patients attained the best possible score for mobility with the FIM and only one-fifth did so using the FIM + FAM. The median FIM and FIM + FAM total scores are both less than the best possible by several points, being 117 (of a possible 126) and 189 (of a possible 210) respectively. Two individuals reached a maximum possible FIM score and only one individual would be rated as without disability according to their FIM + FAM total.

*Correlations between disability measures*

The correlation between the scales is significant ($P < 0.001$) in each case, as summarized in Table 5. However, correlations are much closer between the FIM, FIM + FAM and the OPCS than between the Barthel Index and any of the other scales. As the FIM is incorporated in the FIM + FAM, and accounts for 18 of the 30 items of the latter, it is not surprising that the correlation coefficient is high. The high correlations when comparing the OPCS disability scale with both FIM and FIM + FAM suggests that the OPCS scale detects disabilities with similar sensitivity to these more established scales.

**Table 5.** Relationship between measures (Spearman ranked correlation coefficients)

| | *Barthel Index* | *OPCS Index* | *FIM* | *FIM+FAM* |
|---|---|---|---|---|
| Barthel Index | | 0.489 | 0.642 | 0.525 |
| OPCS Index | 0.489 | | 0.816 | 0.824 |
| FIM | 0.642 | 0.816 | | 0.962 |
| FIM+FAM | 0.525 | 0.824 | 0.962 | |

All results significant at $P < 0.001$

## Discussion

This study evaluated four commonly used outcome measures in patients four to six weeks after leaving hospital. The appropriateness of any measure of outcome after brain injury will vary according to the stage of recovery. In the acute or early rehabilitation period disabilities are often prominent and may overshadow psychosocial issues but by the time the patient is discharged home, cognitive, communicative and behavioural changes may be more evident and contribute considerably to the individual's dependence on others (Gray *et al.*, 1994). If the Barthel ADL Index were used as the sole measure of disability, over two-thirds of the group of patients would be classed as independent while the other measures indicate persisting dysfunction in the great majority. This apparent lack of sensitivity of the Barthel Index is explicable, in part at least, by its focus on physical functions. When only the mobility or self-care components of the OPCS scale, the FIM and FIM + FAM are considered, a sizeable proportion of the study population would also appear independent. It is when total scores are taken into account that the other measures of outcome detect and demonstrate that the patients are unable to perform activities as considered normal for the general population. The limited range of functions evaluated and the ceiling effect of the Barthel Index were among the reasons that stimulated the development of the alternative instruments (Granger *et al.*, 1990; Frattali, 1993). These arguments would seem particularly pertinent in brain-injured people assessed after discharge as in this study. This does not detract from the Barthel Index's robust utility for other purposes and in many other diagnostic groups, particularly stroke (Wade, 1992).

The OPCS scale has compared favourably to the Barthel Index in previous studies of a mixed population of patients, including stroke but not head-injury cases, attending a rehabilitation unit (McPherson *et al.*, 1993) and in survivors of stroke reviewed after one year (Wellwood *et al.*, 1995). Both studies showed good correlations between the two measures and that the OPCS scale was more sensitive to less severe levels of disability than the Barthel Index. The OPCS scale is relatively simple to use, and although certain of its instructions may need clarification, it has been shown to have satisfactory inter-rater reliability (McPherson *et al.*, 1993). In the present study the correlations between OPCS scale and Barthel Index were not as high as in the above reports but this probably reflects the nature of the brain-injured group.

The FIM has been adopted as a measure of disability or rehabilitation internationally in the last few years in a very wide range of disabling conditions including head injury (Granger and Brownscheidle, 1995; Granger *et al.*, 1995). The FIM + FAM, in contrast, was designed specifically for use with brain-injured patients on the precept that brain injury more commonly resulted in diverse cognitive, communicative and behavioural

changes than other disorders did (Hall *et al*; 1993; Pentland and McPherson, 1994). Validity and reliability data on the FIM is increasingly available in the literature (Dodds *et al*; 1993; Ottenbacher *et al*; 1994; Kidd *et al*; 1995) and acceptable inter-rater reliability has been demonstrated recently for the FIM + FAM (McPherson *et al.*, 1996).

In terms of sensitivity in detecting disability in this study, the FIM + FAM appears to provide only a modest advantage over the FIM alone. Only one other individual was captured by the former when total scores are compared (Table 4). When subscales are considered, the two scales differ in only one self-care item (swallowing), thus it is not surprising that no difference in detection of disability is evident. The additional FAM mobility items are car transfers and community mobility, the latter referring to the ability to use public transport. Difficulties with these activities explain the lower proportion of subjects achieving best possible scores on the FIM + FAM than on the FIM mobility subscale.

The high correlation between FIM and FIM + FAM scores was predictable on the basis of one instrument being derived from and sharing many items with the other. However the close correlation between OPCS scale and these two measures provides evidence of concurrent validity of the OPCS. Clearly, further comparative studies are required but if these confirm that the OPCS scale does have similar sensitivity to the FIM in particular, there could be important implications for future studies. While the FIM requires training in scoring methodology and is designed for use by health care professionals, the OPCS scale is amenable to application by non-professionals and might, therefore, be easier to use in certain studies.

No single measure of outcome is ever likely to meet the needs of all individuals wishing to study recovery from brain injury. The specific aims of the investigator(s), the severity of initial damage, time since injury and whether the study is of people in hospital or in the community, are some of the many relevant factors. It is likely that in many instances more than one instrument will need to be used simultaneously. In the present investigation of brain-injured people after discharge from hospital, the most sensitive measure was the FIM + FAM, but both the FIM alone and the OPCS scale were also successful in detecting disability.

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# Relationships Between Cognitive Impairments and Functional Performance After Brain Injury, as Measured by the Functional Assessment Measure (FIM+FAM)

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In recent years there has been an increased recognition of the complex nature of the consequences of brain injury, and an expansion of rehabilitation services for this group. This has been accompanied by the emergence of a number of functional outcome measures which include cognitive, communicative, and psychosocial performance in addition to physical activities of daily living. This paper studies the relationship between one of these global measures, the Functional Assessment Measure (FIM+FAM), in dimensions of cognitive behaviour with standardised neuropsychological tests of attention, orientation, and memory in 52 subjects undergoing early brain injury rehabilitation. A degree of content validity for the FIM+FAM items is shown and a case is made for the complementary use of such outcome measures in association with detailed neuropsychological assessment.

## INTRODUCTION

The welcome and long overdue development of rehabilitation services in recent years for those who survive head injury has been paralleled by increasing attention to the audit of health service activities, including the impact of rehabilitation interventions. While innovations in health care funded on a

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research basis are scrutinised by the funding organisations concerned, established services are being examined for cost-effectiveness by purchasers who desire standardised measures of outcome (Frattali, 1993; Pentland & McPherson, 1994). The process of rehabilitation is aimed at both assisting restoration of function and preventing avoidable secondary dysfunction, making the challenge of measuring outcome considerable. The spectrum of dysfunction that may follow brain injury is protean ranging from severe physical incapacity to profound handicap due to cognitive and behavioural problems. These problems require a range of professional skills and most programmes of rehabilitation are multiprofessional. In addition, recovery often extends over many months or years and the profile of the individual patient's difficulties changes over this time with psychosocial problems becoming increasingly predominant as time passes (Oddy, Humphrey, & Uttley, 1978).

In assessing functional status in a brain injured population, it is essential to employ measures which take account of the heterogeneity of dysfunctions which characterise it. Activities of daily living (ADL) measures, such as the Katz and Barthel indices (Katz et al., 1963; Mahoney & Barthel, 1965), are limited in scope to physical issues and do not address cognitive, communicative, and psychosocial function (Frattali, 1993). Meanwhile, many measures of cognition, although able to assess the nature and level of impairment, are criticised for being unrelated to the "real-life" functional performance (level of disability) of the individual (Newcombe & Artiola i Fortuny, 1979; Ponsford & Kinsella, 1991; Sunderland, Harris, & Baddeley, 1983).

Recognition of the limitations of such measures has led to the emergence of more global measures of rehabilitation, particularly in the United States (Frattali, 1993; Hall, Hamilton, Gordon, & Zasler, 1993; Harvey & Jellinek, 1983). Among the most commonly used of these is the Functional Independence Measure (FIM), devised by a national task force of clinical, research, and administrative experts in rehabilitation as an instrument for general use in rehabilitation practice (Hall et al., 1993; Hamilton et al., 1987). An expanded version, the Functional Assessment Measure (FIM+FAM) was developed specifically for the brain injured population by the addition of 12 items to the 18 items of the FIM with emphasis on cognitive, communicative, and psychosocial functioning (Ditunno, 1992; Hall, 1992; Pentland & McPherson, 1994).

The FIM+FAM is designed to convey shared information within the multiprofessional rehabilitation team and to be suitable for scoring by any trained member of the team. Rather than replacing the requirement for detailed discipline-specific assessments of the patient, it should provide interdisciplinary data which complement other findings of the team. This study compares the FIM+FAM ratings of the dimensions of comprehension, problem solving, memory, orientation, and attention with the results of standardised neuropsychological tests.

## METHOD

### Assessment Procedures

All patients admitted after brain injury for early inpatient rehabilitation to our neurorehabilitation unit are assessed using the FIM+FAM during the first week and subsequently at 4-weekly intervals or at discharge. In addition, the clinical psychologist administers a battery of standardised neuropsychological tests within 3 days of admission. The tests described in this study represent those routinely used within the unit for the detection of attention and memory deficit but do not account for all the measures used in neuropsychological evaluation of patients.

### Functional Assessment Measure (FIM+FAM)

The FIM+FAM comprises 30 items of activity each of which is rated on a 1–7 ordinal scale, with a score of 1 indicating total dependence on another person for the activity, and 7 representing complete independence in the function (Hall et al., 1993). Nurses, therapists, and clinical psychologists contribute to the rating which is agreed by the team. The use of the instrument in the unit has been described elsewhere (Pentland & McPherson, 1994). For the purposes of this study we concentrated on the following FIM+FAM dimensions, each of which focuses on cognitive function; comprehension, problem solving, memory, orientation, and attention.

### Tests of Attention, Memory, and Orientation

Attention was evaluated using the Stroop Colour Word Task (Stroop, 1935), Trail-making Test Part B (Reitan, 1958) and the Digit Span subset of the Wechsler Adult Intelligence Scale—Revised (WAIS-R) (Wechsler, 1981). The Stroop was chosen as a measure of selective attention, the ability to focus attention and inhibit distraction. Part B of the Trail-making Test was used to assess the reciprocal ability of shifting attention between simultaneous demands efficiently and flexibly. Digit Span was incorporated to investigate "passive" attentional capacity (Digits Forwards), together with the more active and manipulative mental control aspect of attention (Digits Backwards).

The Delayed Story Recall (Coughlan & Hollows, 1988) and Delayed Complex Figure Recall (Rey, 1964) were used as tests of recent memory and were predicted to reflect the assessment of both visual and verbal memory in the FIM+FAM memory dimension.

The Trail-making B and Delayed Complex Figure Recall tests were among the neuropsychological tests found to relate to functional outcome as assessed by the Glasgow Outcome Scale (Clifton et al., 1993). A verbal recall test, similar to the Delayed Story Recall has been described as a useful predictor of return to work (Brookes et al., 1987).

Orientation was rated from the Galveston Orientation and Amnesia Test (GOAT) (Levin, O'Donnell, & Grossman 1979) and the Mini Mental State Examination (MMSE) (Dick et al., 1984).

For the five test of memory and attention described above, test data were converted into percentile scores using normative data from the cited references and Lezak (1995), corrected for age but not for educational background. These percentiles were then ranked into six levels of neuropsychological test performance (Table 1) for ease of comparison with the seven-level FIM+FAM. Such norms were not available for the GOAT or the MMSE and thus raw scores were used.

It should be noted that the designated percentile level only reflects the subjects' neuropsychological performance relative to normative test data. Thus, it does not indicate actual level of individual neuropsychological impairment in terms of estimated discrepancy between premorbid and current attainment. Measuring impairment in this normative rather than individualised manner was necessary to ensure a common comparison standard for both neuropsychological and functional measurement. In other words, to test the a priori assumption that a FIM+FAM score of 6 or 7, is equitable with average neuropsychological performance and, that below average scoring on the measures might be reflected in lower functional ratings. Such a relationship between impairment and disability could not be assumed if an individualised definition of neuropsychological impairment had been used.

## Statistics

Spearman rank order correlation coefficients were calculated comparing each neuropsychology test with the related FIM+FAM items.

To further compare the two methods of assessment, the neuropsychology test results were divided into two groups, "average and above" ( > 25th percentile) and "below average" ( ≤ 25th percentile). The MMSE Total score was also divided into two groups: "average and above" (23–30) and "below average" ( ≤ 23). The MMSE Orientation score was divided into two groups: "average

TABLE 1
Grouping of Neuropsychology Test Results

| *Percentile ranking* | | *Level* |
|---|---|---|
| > 90 | Well above average | 6 |
| 75–90 | Above average | 5 |
| 25–75 | Average | 4 |
| 10–25 | Below average | 3 |
| 2–10 | Well below average | 2 |
| < 2 | Impaired | 1 |

(< 2 = over 2 standard deviations below mean).

or above" (6–10) and "below average" ( $\leq 6$). Mann Whitney *U* tests were performed to determine whether any significant differences existed between the two groups on any of the FIM+FAM items. The GOAT scores may be grouped into three, according to the following scores: 76–100 = "average and above", 66–75 = "borderline", and below 65 = "below average". Kruskal–Wallis analysis of variance was used to estimate whether the difference across the three groups was significant.

## RESULTS

### Patients

A total of 52 patients, of whom 30 were male, were included in the study. Their median age was 43 years (range 16–73 years). Twenty-seven had suffered a closed head injury and the other 25 had a spontaneous intracranial haemorrhage confirmed by computed tomography (CT) scan. The median time between injury and assessment was 35 days (range 7–77 days). Glasgow Coma Score (GCS) on admission was available on 34 patients and showed that the majority (70%) had sustained a severe brain injury (GCS < 8).

Patients were only tested if they clearly understood the test instructions and had emerged from post traumatic amnesia (PTA) as assessed by free recall over a 24-hour period of previously presented objects and information about the examiner (such as name, role). No patient had a PTA of less than 5 days. Using the classification suggested by Jennett and Teasdale (1981), 9% had a severe injury (1–7 days), 63% a very severe injury (1–4 weeks), and the remaining 28% an extremely severe injury (more than 4 weeks).

The level of orientation, degree of speech and language disturbance as well as visual processing disorder were assessed immediately prior to neuropsychological examination. A description of these characteristics is provided in Tables 2, 3, and 4.

Assessment of orientation was based on clinical interview whilst clarification of speech and language disturbance was based on a formal speech therapy assessment. Coding of visual deficit was based on admission neurological screening and, in cases of unilateral spatial neglect or higher level visual processing disturbance, on contemporaneous neuropsychological assessment.

TABLE 2
Level of Orientation from Clinical Interview

| *Level* | *Number of patients* | *%* |
|---|---|---|
| Person only | 11 | 21 |
| Person and place | 13 | 25 |
| Person, place, and time | 28 | 54 |

TABLE 3
Degree of Speech and Language Disturbance

| *Description* | *Number of patients* | *%* |
|---|---|---|
| Mixed dysphasia | 1 | 2 |
| Receptive dysphasia | 2 | 4 |
| Expressive dysphasia | 4 | 8 |

TABLE 4
Sensory and Cortical Visual Processing Disorder

| *Disorder* | *Number of patients* | *%* |
|---|---|---|
| Diplopia | 5 | 10 |
| Homonymous hemianopia | 3 | 6 |
| Colour blindness | 2 | 4 |
| Reduced visual acuity | 3 | 6 |
| Unilateral spatial neglect | 3 | 6 |
| Visual spatial/perceptual disorder | 3 | 6 |

Motor dysfunction precluded three patients from using their preferred hand for the Trail-making B and Rey Complex Figure tests. Observation of the patients' behaviour in the ward and during testing was used to gain gross indication of the frontal characteristics of the sample. On this basis, 13 (25%) patients displayed perseveration, eight (15%) confabulation and four (8%) had clear anger control difficulties.

One individual had been diagnosed as having early Parkinson's disease. There was a history of alcohol abuse in 10 (19%) of the subjects, including two who had also abused amphetamines in the past. One subject was hospitalised with bipolar affective disorder at the time of her neurological episode.

The vast majority, 44 (85%), of subjects were in employment or full-time education prior to their neurological insult. The mean period of school attendance was 11 years with 10 (19%) subjects having proceeded to tertiary education.

## Neuropsychology Test and FIM+FAM Item Scores

The level of performance of subjects in each of the neuropsychological measures and FIM+FAM dimensions is summarised in Table 5. The proportion of subjects performing at average and above or below average on each of the neuropsychological measures is summarised in Table 6. Those subjects who were unable to complete the task are also noted.

## Correlations

Spearman ranked order correlation coefficients, comparing each of the three neuropsychological impairment dimensions with the five FIM+FAM items are shown in Table 7. Of the three attentional tests, only the Trail-making B reached a significant level of positive correlation with the FIM+FAM attention rating. The two tests of memory, Story and Complex Figure Delayed Recall, both correlated significantly with the FIM+FAM memory item but it is noteworthy that both relate strongly to other FIM+FAM cognitive items. For example,

TABLE 5
Median and Mean Level Attained in Each Test

| *Test name* | *Median* | *Mean* | *SD* | N |
|---|---|---|---|---|
| Neuropsychology—Attention | | | | |
| Stroop | 1 | 2.08 | 1.42 | 37 |
| Trail-making B | 2 | 2.36 | 1.37 | 45 |
| Digit Span | 4 | 3.52 | 1.28 | 52 |
| Neuropsychology—Memory | | | | |
| Story Recall | 2 | 2.25 | 1.27 | 52 |
| Rey Complex Figure | 1 | 1.80 | 1.25 | 51 |
| Orientation Screening Test | | | | |
| GOAT (Total) | 69.5 | 57.93 | 29.36 | 16 |
| MMSE (Total) | 24 | 22.06 | 6.19 | 48 |
| MMSE (Orientation) | 8 | 6.8 | 2.75 | 50 |
| FIM+FAM Dimension | | | | |
| Comprehension | 6 | 5.5 | 1.58 | 52 |
| Problem solving | 4 | 4.04 | 1.73 | 52 |
| Memory | 4 | 3.92 | 1.74 | 52 |
| Orientation | 5 | 4.54 | 2.00 | 52 |
| Attention | 5 | 4.35 | 1.80 | 52 |

Story Recall also correlates highly with functional ratings of orientation and comprehension. Indeed, delayed recall of the complex figure correlates slightly more with the FIM+FAM orientation and problem solving rating than for memory. However, the delayed recall of the complex figure does not relate to the FIM+FAM comprehension dimension. The orientation tests correlated somewhat better with the corresponding functional dimension but again there is a lack of specificity.

TABLE 6
Number of Patients in Each Group

| *Test* | *Number of patients tested* | *Below average* n | % | *Average or above* n | % | *Unable to complete* n | % |
|---|---|---|---|---|---|---|---|
| Stroop | 40 | 27 | 68 | 10 | 25 | 3 | 7 |
| Trail-making B | 48 | 34 | 71 | 11 | 23 | 3 | 6 |
| Digit Span | 52 | 18 | 35 | 34 | 65 | – | – |
| Story Recall | 52 | 40 | 77 | 12 | 22 | – | – |
| Rey Complex Figure | 51 | 45 | 88 | 6 | 12 | – | – |
| GOAT | 16* | 7 | 44 | 5 | 31 | – | – |
| MMSE (Total) | 48 | 23 | 48 | 25 | 52 | – | – |
| MMSE (Orientation) | 50 | 20 | 40 | 30 | 60 | – | – |

*Four patients (25%) were "borderline" on GOAT.

TABLE 7
Correlation (Spearman Ranked Correlation) of FIM+FAM Dimension and Neuropsychology Tests

| | *FIM+FAM Dimension* | | | | |
|---|---|---|---|---|---|
| *Neuropsychological test* | *Comprehension* | *Problem solving* | *Memory* | *Orientation* | *Attention* |
| Stroop ($n = 37$) | 0.31 | 0.34 | 0.35 | 0.54** | 0.36 |
| Trail-making B ($n = 45$) | 0.48* | 0.45* | 0.45* | 0.49* | 0.39* |
| Digit Span ($n = 52$) | 0.50* | 0.34 | 0.42* | 0.34 | 0.31 |
| Story Recall ($n = 52$) | 0.53** | 0.41* | 0.51* | 0.52* | 0.44* |
| Rey Complex Figure ($n = 51$) | 0.15 | 0.41* | 0.36* | 0.46* | 0.36* |
| GOAT (Total) ($n = 16$) | 0.69* | 0.54 | 0.55 | 0.69* | 0.45 |
| MMSE (Total) ($n = 48$) | 0.56** | 0.53** | 0.60** | 0.62** | 0.42* |
| MMSE (Orientation) ($n = 50$) | 0.52** | 0.57** | 0.56** | 0.66** | 0.51* |

*$P < 0.01$, **$P < 0.001$.

## Difference between FIM+FAM dimension score according to neuropsychological tests group

The median FIM+FAM score for those grouped as average and above, below average, or unable to complete for each of the neuropsychological tests are compared in Figs. 1–8. The GOAT scores (Fig. 8) include a borderline group. A dotted line is marked in Figs. 1–8 at the FIM+FAM score of 5, which indicates the level at which supervision is required. The FIM+FAM scores for the below average group (and those for the unable to complete group) suggest the need for assistance from others. However, those from the average or above group are in most cases greater than 5 suggesting supervision only, or greater independence. In most cases the difference between the two groups is signifi-

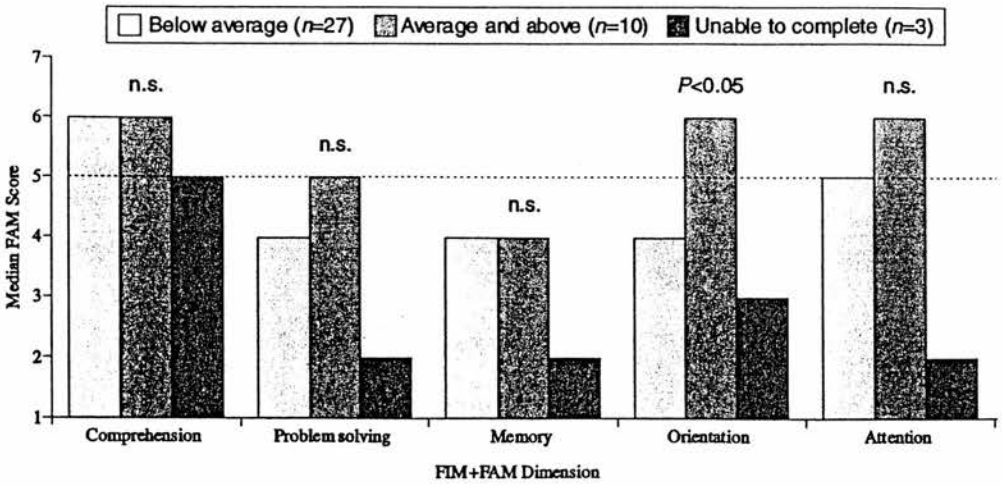


FIG. 1. Stroop group related to FIM+FAM score.

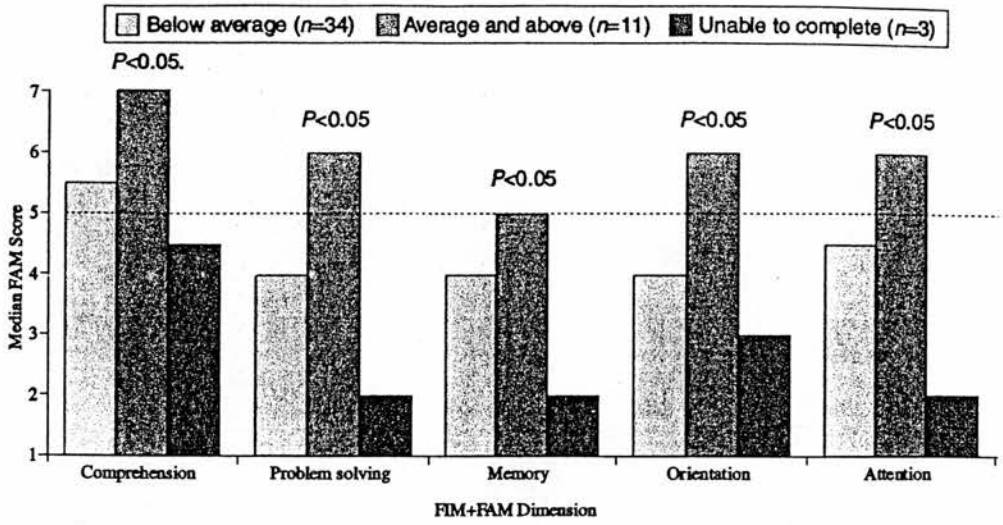


FIG. 2. Trail-making B Test Part B group related to FIM+FAM score.

cant with the exception of the Stroop test. The most significant differences between the two groups were found in Story Recall and MMSE.

## DISCUSSION

As its name implies, the Functional Assessment Measure (FIM+FAM) is designed to grade functional abilities or disabilities, and is based on observation of behaviour. It is scored according to the relative dependence of the subject upon others for each item rated. In contrast, traditional neuropsychological

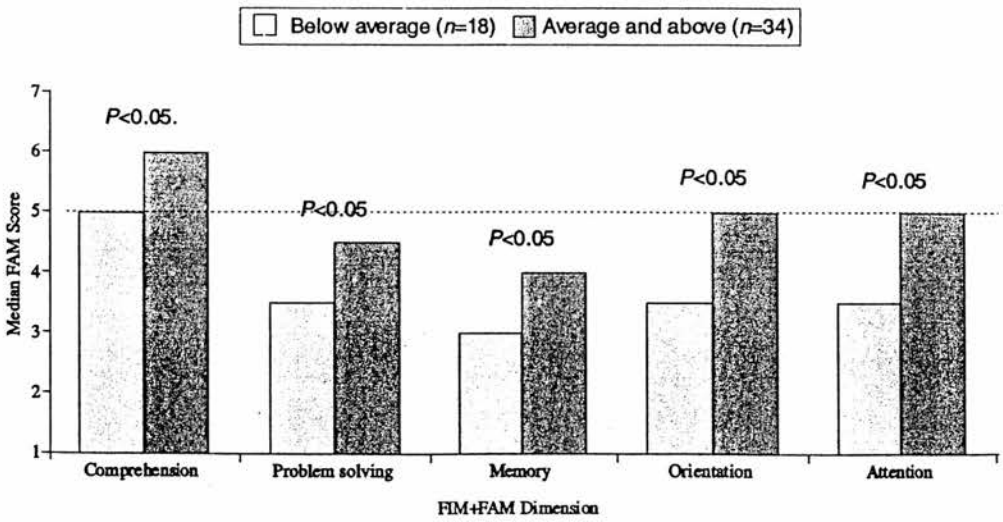


FIG. 3. Digit Span group related to FIM+FAM score.

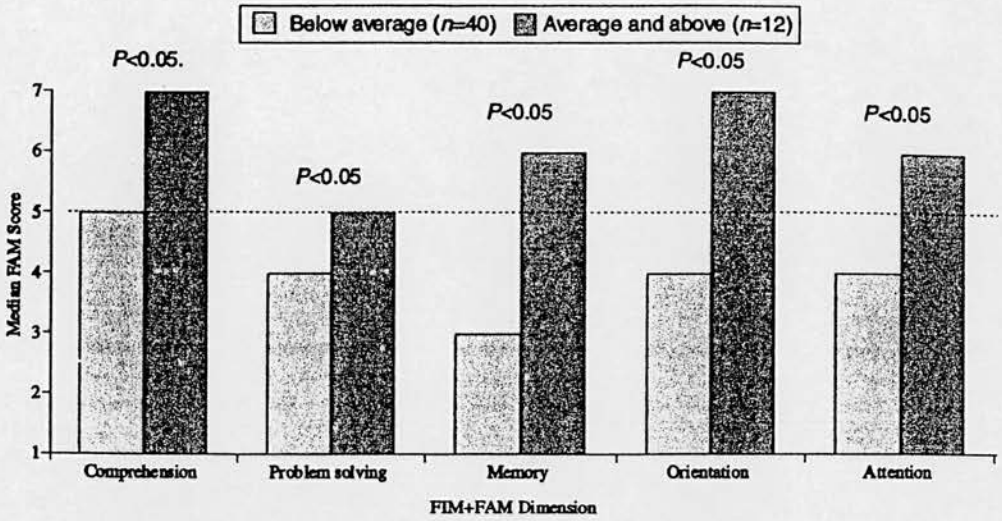


FIG. 4. Story Recall group related to FIM+FAM score.

testing is directed at establishing levels of cognitive impairment. Such tests are at best, as Diller and Ben-Yishay (1987) have emphasised, indirect markers that reflect functional outcome rather than being functional outcome measures in themselves. However, both these approaches use the common terms comprehension, attention, memory, and orientation.

The World Health Organisation's *International classification of impairments, disabilities and handicaps* (ICIDH) lists impairments in these four categories but does not explicitly use these precise words to classify disabilities (WHO, 1980). It does recognise "disability in understanding speech" and "knowledge acquisition disability" which are certainly relevant to comprehen-

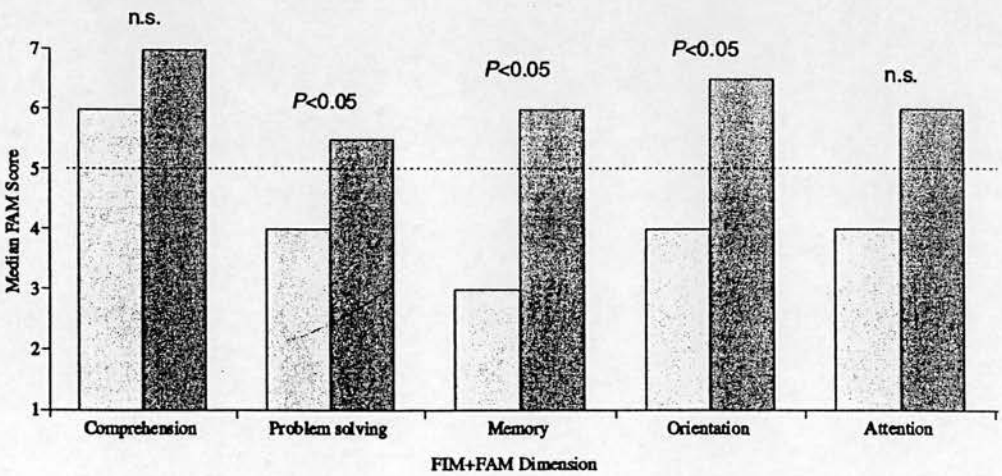


FIG. 5. Rey Complex Figure group related to FIM+FAM score.

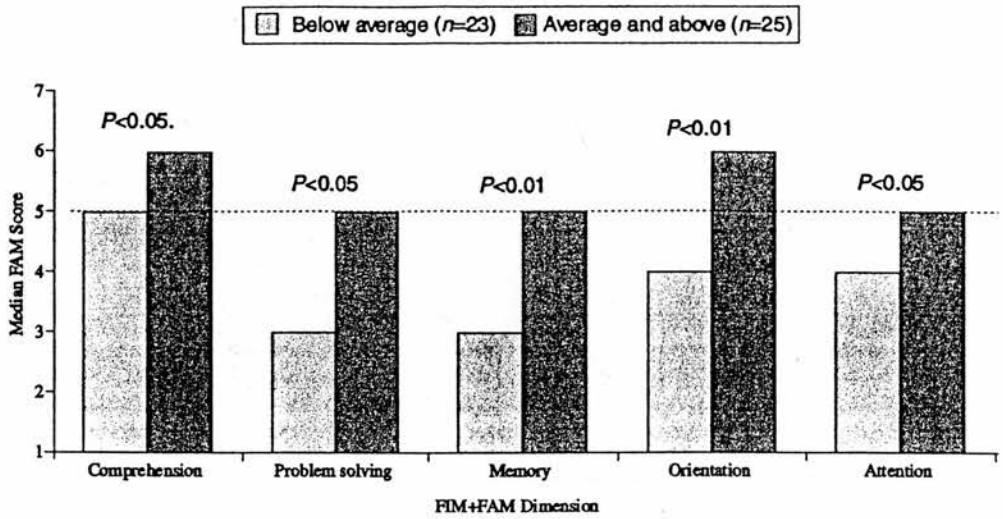


FIG. 6. MMSE total group related to FIM+FAM score.

sion and memory. However, these aspects are not as clearly linked to the underlying impairments as is the association between many physical disabilities and impairments. Given that disability, and indeed dependence following brain injury, may relate as much to difficulties in the performance of cognitive functions as to physical limitations, both cognitive impairment and cognitive disability must be assessed. Indeed, there is a growing awareness that failure to assess functional aspects of cognition may result in a tendency merely to speculate on which disabilities or handicaps may occur (Ponsford & Kinsella, 1991). This in turn may lead to the functional consequences of cognitive

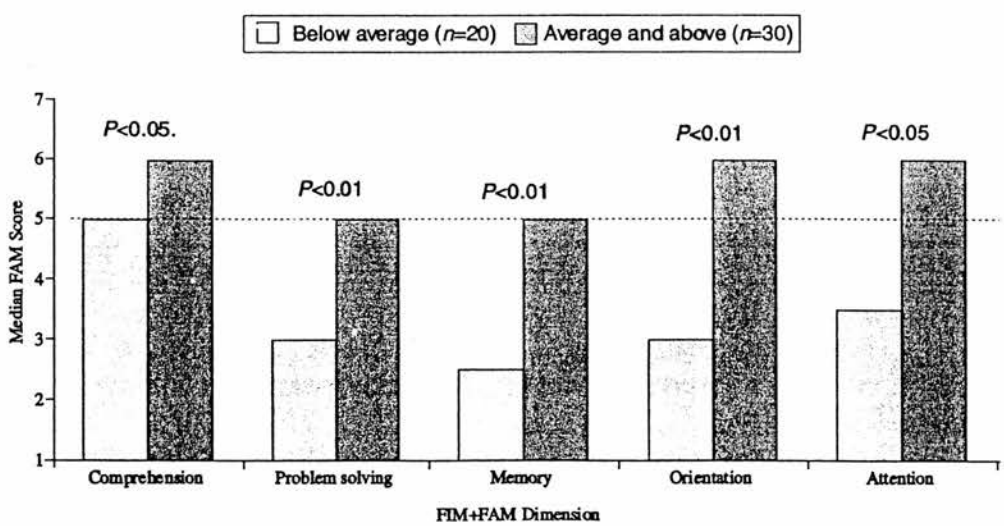


FIG. 7. MMSE Orientation group related to FIM+FAM score.

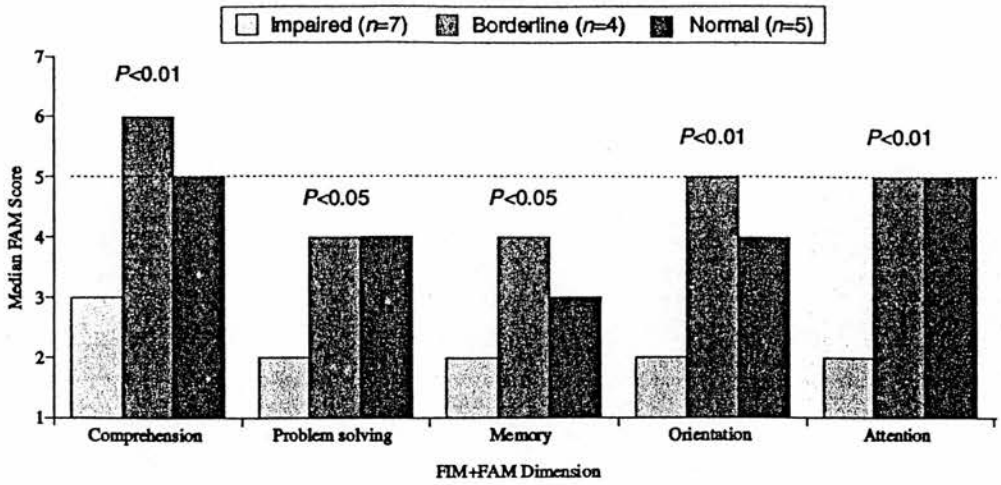


FIG. 8. GOAT group related to FIM+FAM score.

impairment being understood (or overestimated) and it may prevent the implications of cognitive impairment being fully understood by both providers and purchasers of service.

The use of the terms comprehension, attention, memory, and orientation in instruments such as the FIM+FAM, while extending the view of disability, may cause some confusion. However, other disability measures, such as the Disability Rating Scale (Rappaport et al., 1982), the Patient Evaluation and Conference System (Harvey & Jellinek, 1983) and the Office of Population, Censuses and Surveys, Scales of Disability (OPCS) (Martin, Meeler, & Elliot, 1988) also include cognitive and behavioural dimensions. It is difficult to suggest succinct or single word alternatives for real-life measurement of such functions. It might be worth simply accepting the use of the terms but distinguishing between "comprehension impairment" and "comprehension disability" etc., according to the context and method of testing.

It is suggested here, and elsewhere (Hart & Hayden, 1986; Pentland & McPherson, 1994; Ponsford & Kinsella, 1991), that a conceptual framework of disability following brain injury must include a focus on functional aspects of cognition. Based on this assumption, the present study was designed to examine how dependence in cognitive functions, as measured by the FIM+FAM, relates to impairment-based cognitive assessments. It should also be emphasised that this study was based on early brain injury rehabilitation cases where the degree of damage was often severe, and was based on initial evaluation within days of admission.

The relatively strong relationship between functional comprehension ratings and attention test performance, although anticipated to some extent by the overlap in these concepts, may also be exacerbated by the generally low cognitive level of subjects in this study. This is likely to lead to both sets of

scores being disproportionately reflective of problems assimilating information, rather than more circumscribed deficits of understanding and attention.

In the case of memory and orientation, a significant relationship does exist between the disabilities measured by the FIM+FAM and the respective neuropsychological tests of impairment. With regard to orientation, these findings are not surprising as the FIM+FAM employs questions on orientation in time and place which are similar to those used in the GOAT and MMSE. Memory, by contrast, is evaluated in terms of everyday function on the FIM+FAM, and did correlate with the memory impairment on the two neuropsychology tests described.

Although the vast majority of subjects were able to attempt all tests, the range of accomplishments as a group is very restricted. A major reason for this is clearly the notably ubiquitous presence of slowed information processing and mental fatigue effects in the sample. It can be seen from Table 5 that with the exception of Digit Span, median performance on the psychological tests was well below average (i.e. below the 10th percentile). This level of generalised cognitive disruption across the sample may be contributing to the lack of specificity in the relationship of FIM+FAM scores to neuropsychological test results.

A further explanation may well be that the FIM+FAM cognitive dimensions lack specificity in their definition, leading to uncertainty amongst raters about what emphasis to place on different aspects of the cognitive process they are observing. With regard to attention, it can be noted that the Trail-making B was the only attentional measure to be associated with the disability rating of attention. This may be because Trail-making B involves a larger sustained attention component than the other two tests. Perhaps the FIM+FAM rating is made primarily on the basis of sustained concentration over time although other aspects of attention are mentioned in the item definition. The incorporation of several different cognitive variables within one FIM+FAM item may be contributing to the lack of specificity found.

A FIM+FAM score of 6 or 7 indicates that no help or supervision is required in the activity. A score of 5 indicates that supervision only is needed and a score of less than 4 indicates that some degree of assistance is necessary. In the Trail-making B, Story Recall, Rey Complex Figure and MMSE, those scoring average and above required no more than supervision for each of the FIM+FAM dimensions assessed. Those scoring below average on the neuropsychological tests required a greater degree of assistance and in many cases this difference in the level of support required was significant. There is, therefore, a clear relationship between test performance and the individual's need for help or supervision in everyday functioning. The Stroop test was the only one where the differences in FIM+FAM score were predominantly insignificant.

As described above, the FIM+FAM is a derivative of the shorter Functional Independence Measure (FIM). Of the five dimensions of the FIM+FAM

examined in this study, three are components of the FIM: comprehension, problem solving, and memory. We are not aware of comparisons of these FIM dimensions with neuropsychological tests in people with brain injury, but Davidoff, Roth, Haughton, and Ardner, (1990) reported a study following traumatic spinal cord injury. They grouped problem solving, memory, and another dimension, social interaction, together as a "social cognition" subscale, and comprehension with expression as a "communication" subscale of the FIM. They then investigated the sensitivity of these subscales, compared with a battery of neuropsychology tests. In this group of 41 patients, they found that, with the exception of one, on one item (problem solving), the FIM ratings were 6 or 7, and mostly 7. In contrast, a significant proportion of patients had evidence of some cognitive impairments on their battery of neuropsychological tests. Their conclusion was that instruments such as the FIM had substantial false negative rates and may be insensitive to mild or moderate neurocognitive impairment (Davidoff et al., 1990). However, another study of the FIM in spinal cord injury (Dahlberg et al., 1990) showed that those patients assessed as having cognitive impairment on neuropsychological tests had significantly lower scores on the FIM social cognition and communication subscales. Our study with brain injured subjects indicated that the FIM+FAM was sensitive to detecting functional consequences of cognitive deficit when compared with the neuropsychological tests. However, we would acknowledge the significant risk of false negatives if instruments are not used in association with skilled neuropsychological assessment.

Such characteristics of the FIM+FAM highlight the need for further exploration of its psychometric properties. Difficulties establishing adequate inter-rater reliability for observational scales of cognitive behaviour are not uncommon (Ponsford & Kinsella, 1991). In a previous study to evaluate the inter-rater reliability of the FIM+FAM (McPherson, Pentland, Cudmore, & Prescott, 1996), the five FIM+FAM items referred to here were shown to have satisfactory reliability, albeit not as robust as those items concerned with physical functioning. Given the complexity of mental functioning (Diller & Ben-Yishay, 1987), this is perhaps unsurprising.

Interpreting individual tests of cognitive impairments in isolation is wholly inappropriate, and this was not the intention of this study. It is imperative to have a detailed knowledge of the extent and range of underlying cognitive impairments to understand the cause of functional deficits and to plan interventions to assist in recovery from, or adaptation to them.

The present study indicates that FIM+FAM cognitive ratings of severely brain injured patients early in their rehabilitation broadly relate to levels of cognitive impairment as measured by neuropsychological tests. Further, dependency in these functions as illustrated on the FIM+FAM, is significantly different according to whether impairment is present on the relevant neuro psychological tests (Figs. 1–8). However, as shown in Table 7, there is

clearly a lack of specificity in the relationship between the FIM+FAM dimensions and the corresponding neuropsychological tests. As suggested earlier, it appears that the severity of injury in this group, and the short interval between insult and neuropsychological testing, are contributing to a generalised slowing of cognitive processing. Thus, rather than specific deficits relating to specific functional consequences, one finds that an impairment in any cognitive domain is associated with a broad range of functional consequences for the individual as reflected by the FIM+FAM. It may well be that at this early stage of recovery, the capacity of both FIM+FAM cognitive items, and neuropsychological measures to detect specific mental deficits, are likely to be overwhelmed by the generally widespread and severe nature of cognitive disturbance.

Another factor to consider in this lack of specificity is that the FIM+FAM may only be able to reflect broad cognitive function. However, discussion regarding the extent to which FIM+FAM cognitive dimensions are sensitive to more discreet intellectual effects, elucidated by neuropsychological measures administered at a later stage of recovery, requires further investigation. Smith-Knapp, Corrigan, and Arnett (1996) examined the association between a range of neuropsychological tests and the FIM in a group of patients discharged from inpatient rehabilitation following traumatic brain injury. They describe a similar degree of relationship between the neuropsychological test battery, and both the motor and cognitive subscales of the FIM. Indeed, only one of the neuropsychological tests (the WAIS-R comprehension) was found to be predictive of the FIM cognition score. However, Smith-Knapp's study was also done within the first month following injury (mean time 24 days, SD 17.8).

We would agree with others (Johnstone, 1996) that investigation of the relationship between neuropsychological tests and functional abilities is essential. This study further highlights the clinical difficulty of assessing cognitive impairment soon after insult, and relating that to the specific functional consequences experienced by the individual.

There is a need to study further the relationship between functional scales, such as the FIM+FAM, and a wider range of cognitive instruments at different time periods following insult. In particular, it would be useful to investigate how the FIM+FAM correlates with neuropsychological evaluations of planning and problem solving abilities. Given the increasing uncertainty of conventional neuropsychological assessments accurately to predict functional performance, it would be interesting to investigate how the FIM+FAM compares with the limited number of assessments available that are specifically designed to be more sensitive to everyday consequences of cognitive impairment such as the Rivermead Behavioural Memory Test (Wilson, Cockburn, & Baddeley, 1985) and the Test of Everyday Attention (Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994). Such research would not only assist the development of functional measures such as the FIM+FAM, but also would provide an impetus

within brain injury rehabilitation for the development of more ecologically valid cognitive measures.

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Manuscript received 10 April 1995
Revised manuscript received 16 October 1995

**RON FORM**

DATE __/__/__

SURNAME _____ FIRSTNAME_____

ADDRESS_____

_____

_____

POSTCODE _____ TELEPHONE NUMBER _____

Study no_____ Initial G.C.S_____ 6 hour GCS_____ PTA_____ DOB_____ AGE _____

DEMOGRAPHIC INFORMATION

1) Date of injury/insult __/__/__

2) Type of injury (Traumatic[1]/Haemorrhagic[2]/Anoxic[3]/Other[4]) [ ]

3) Duration in Acute Care (days) [ ]

4) Duration in Rehabilitation (days) [ ]

5) Time since discharge (days) [ ]

6) Principal Condition _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Other conditions _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Surgical Procedures _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

7) Marital Status (marr[1]/sing[2]/divo[3] / sepa[4]/wido[5]/othe[6]) [ ]

8) Living situation (alone[1]/partner[2]/others[3]/institution[4]) [ ]

9) Housing (local[1]/owner[2]/rent[3]/shelt[4] / part4[5]/nurse[6]/ other [7]) [ ]

10) Other relevant information

SEMI-STRUCTURED INTERVIEW - PATIENT

1) What are the main problems for you at the moment?

---

---

2) What do you spend the day doing?

---

---

Is this different to before the brain injury?

---

---

3) What mood do you feel you are in most of the time?

---

(easy going, bad-tempered, tired, bored)

4) What do you need people to do for you?

---

---

5) What 'chores' are you doing around the house?

---

---

Is this different to before the brain injury?

---

---

6) What do you think about working

a) at your old job_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

b) getting a new job_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

c) retraining_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

7) How do you feel about meeting

a) old friends_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

b) relatives_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

c) new people_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

8) Generally - how do you feel things are going?

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

These questions are an attempt to understand the day-to-day needs of 'x'. It might be that I can refer you to the agency that will help, but it may be that the specific help you require is not available. In that event, at least documenting that fact may help to improve services in the future.

4) Are there things you want more information on?

| | Unprompted | Prompted | Details | Action |
|---|---|---|---|---|
| **Physical health** | | | | |
| Continence | | | | |
| Medication | | | | |
| Nature of injury | | | | |
| Level of Help | | | | |
| Alcohol | | | | |
| **Mood** | | | | |
| Behaviour | | | | |
| Cognitive Problems | | | | |
| Boredom | | | | |
| **Social concerns** | | | | |
| Benefits | | | | |
| Work | | | | |
| Day Care / Respite | | | | |
| Driving | | | | |
| **Structures** | | | | |
| Therapy | | | | |
| Follow up | | | | |

Other _____

5) Are there things you need more help with?

_____

6) Are there other areas of worry or concern for you?

_____

SERVICES

| | |
|---|---|
| 10) Home Help..... | |
| 11) District Nurse.... | |
| 12) Health Visitor.... | |
| 13) GP..... | |
| 14) Physio..... | |
| 15) OT..... | |
| 16) Speech..... | |
| 17) Psychologist..... | |
| 18) Day Hospital..... | |
| 19) Day Centre..... | |
| 20) Training Centre | |
| 21) Headway..... | |
| 22) Social Worker... | |

1. Referred/seen 1/52
2. Referred/seen 1/12
3. Referred/not seen/ no action
4. Referred/not seen/ action
5. Not referred/no action
6. Not referred/RON action
7. Refused

| BENEFITS | PROV | N/A | REQUIRE | REFFER |
|---|---|---|---|---|
| | | | | |

Agencies/professionals referred to.

---

---

Other Information

DATE
ASSESSMENT RESULTS Study Number:

**OPCS**

| LOC | RS | DEX | PC | CON | SIGH | HEA | COM | BEH | IF | COS | EDD | DF |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | |

OSS1_ _ _
OSS2_ _ _
OSS3_ _ _
OSSTOT_ _ _ _

**Barthel**

| feed | gr | bow | blad | dres | tran | toile | walk | stair | bath |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |

| | |
|---|---|
| Total | |
| Mobil | |
| S C | |

**ERSS**

| Supp1 | Supp2 | Supp | Inac | Isol | Effsym | Total |
|---|---|---|---|---|---|---|
| | | | | | | |

**FAM**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Self Care | swallow | feed | groom | bath | dress upp | dress low | toilet | bladder | bowel |
| | | | | | | | | | |
| Mobility | bed | toilet | bath | car | walk/whe | stair | | | |
| | | | | | | | | | |
| Commun | compr | expres | read | writ | sp intell | | | | |
| | | | | | | | | | |
| Social | so inter | emotion | adjust | | | | | | |
| | | | | | | | | | |
| Cognitive | prob sol | memory | orient | attent | safety | | | | |
| | | | | | | | | | |
| | employ | com mob | | | | | | | |
| | | | | | | | | | |

## QUESTIONNAIRE FOR RELATIVES

As well as interviewing and assessing the person who was injured, we have found it helpful to ask a relative or close friend how the injured person is progressing. This helps us to make sure that we don't miss symptoms or changes resulting from the injury.

It would therefore be helpful if you would fill in this questionnaire.

Name of injured person .....

Today's date .....

Your own name .....

How are you related to the injured person? .....

Who is the main person who looks after the person who was injured?

.....

The questions which follow are about the injured person's health **over the last few weeks**, compared with how they were before the injury.

**As a result of the head injury, does the injured person suffer problems with:**

| | | | | |
|---|---|---|---|---|
| 6. | **Eyesight** | no change | rather worse since injury | much worse since injury |
| 7. | **Hearing** | no change | rather worse since injury | much worse since injury |
| 8. | **Sense of taste** | no change | rather worse since injury | much worse since injury |
| 9. | **Sense of smell** | no change | rather worse since injury | much worse since injury |
| 10. | **Balance** | no change | rather worse since injury | much worse since injury |
| 11. | **Dizzy spells** | no change | rather worse since injury | much worse since injury |
| 12. | **Headaches** | no change | rather worse since injury | much worse since injury |
| 13. | **Tiredness** | no change | rather worse since injury | much worse since injury |
| 14. | **Difficulty sleeping or disturbed sleep** | no change | rather worse since injury | much worse since injury |
| 15. | **Slowness** | no change | rather worse since injury | much worse since injury |
| 16. | **Tension or anxiety** | no change | rather worse since injury | much worse since injury |

(Please circle which answer applies)

| | | | | |
|---|---|---|---|---|
| 17. | **Impatience** | no change | rather worse since injury | much worse since injury |
| 18. | **Finds noise distressing** | no change | rather worse since injury | much worse since injury |
| 19. | **Irritability** | no change | rather worse since injury | much worse since injury |
| 20. | **Outbursts of temper** | no change | rather worse since injury | much worse since injury |
| 21. | **Outbursts of violence** | no change | rather worse since injury | much worse since injury |
| 22. | **Difficulty speaking (slurred speech or stammer)** | no change | rather worse since injury | much worse since injury |
| 23. | **Difficulty finding the right word** | no change | rather worse since injury | much worse since injury |
| 24. | **Difficulty understanding what words mean** | no change | rather worse since injury | much worse since injury |
| 25. | **Concentration** | no change | rather worse since injury | much worse since injury |
| 26. | **Depression** | no change | rather worse since injury | much worse since injury |
| 27. | **Childishness** | no change | rather worse since injury | much worse since injury |
| 28. | **Sudden changes in mood** | no change | rather worse since injury | much worse since injury |

29. **Has the patient's personality changed as a result of the injury?**

No Yes

30. **Has the patient become more passive, "not bothered" or has he/she less drive?**

No To some extent Very much so

31. **Is the patient's memory worse than before the injury?**

No different Rather worse Much worse

If the patient's memory is worse, please answer these questions by circling "yes" or "no".

| | | | |
|---|---|---|---|
| a | **Do they forget the names of acquaintances?** | Yes | No |
| b | **Do they mislay things?** | Yes | No |
| c | **Do they fail to recognise faces or places?** | Yes | No |
| d | **Do they forget things which you tell them?** | Yes | No |
| e | **Do they forget what day it is?** | Yes | No |
| f | **Do they get lost if they go out alone?** | Yes | No |

33. **Has the patient suffered any fits since discharge from hospital?**

None Occasional Regular

34. **Does the patient need to take tablets to prevent fits?**

No Yes

35. **As a result of the injury, is the patient disabled to the extent that stick, crutches, wheelchair etc are needed to get about by himself/herself?**
Please tick one

Fully independent, that is, no aids and no difficulty getting about
Gets about without aids but with some difficulty
Needs a stick/crutches
Confined to wheelchair, can move self in it
Confined to wheelchair, needs pushing
Confined to bed

36. **Has the patient's sex life changed since the injury?**
Not adversely affected Adversely affected Don't know

37. **Is the patient independent in self care (washing, dressing, toileting)?**
No change due to injury Needs more help Needs a lot more help

38. **Does the patient need supervision outdoors?**
No change due to injury Needs more help Needs a lot more help

39. **Does the patient need supervision indoors?**
No change due to injury Needs more help Needs a lot more help

40. **Is the patient attending any outpatient clinics?**
Yes No

If "yes" please specify .....

41. **What is the patient's NORMAL employment?**

.....

(Please circle which answer applies)

42. **Just before the injury, what was the patient's work status?**

| | | | |
|---|---|---|---|
| Working full-time | Working part-time | Housewife | Student |
| Retired | Unemployed | Unfit for work | School child |

43. **Please describe briefly the patient's PRESENT occupation (if any)**

.....

44. **At the present time, what is the patient's work status?**

| | | | |
|---|---|---|---|
| Working full-time | Working part-time | Housewife | Student |
| Retired | Unemployed | Unfit for work | School child |

45. **Do you think the patient's future employment prospects have been affected by the injury?**

Not affected  Affected to some extent  Very much worse

46. **Has the patient's leisure and social life changed since the injury?**

Little or no change  Rather worse since injury  Much worse since injury

47. **Who was to blame for the injury?**

Patient's own fault.....Another person was to blame .....
Not known .....  Other (describe) .....

48. **Has there been/will there be an action for compensation?**

Yes  No

49. **Is this settled?**

Yes  No

50. **How much strain have you yourself been under as a result of the injury?**
Place a tick somewhere from 0 = no strain to 10 = severe strain

0 ——————————————————————— 10

No strain  Severe strain

51. **Has the patient become less sociable since the injury?**

No change  A bit less  Much less

52. **Has the patient been more outgoing or friendly since the injury?**

No change  A bit more  Much more

53. **Has the patient been less tactful or well-mannered since the injury?**

No change  A bit less  Much less

54. **Has the patient's behaviour changed for the worse since the injury?**

No change  A bit worse  Much worse

(Please circle which answer applies)

55. **Has the patient been looking after him/herself - keeping clean and tidy?**
No change Less care Much less

56. **Compared to before the injury, does the patient take an active part in household tasks?**
No change Less Much less

57. **Does the patient play the same part in making decisions as he/she did before the injury?**
No change A bit less Much less

58. **Does the patient chat about everyday things (news, local events) and take an interest in what you are doing?**
No change A bit less Much less

59. **Have you been able to discuss problems and worries with the patient since the injury?**
No change A bit less Much less

60. **Is the patient as warm and affectionate towards you since the injury?**
No change A bit less Much less

If applicable:

61. **Compared to before the injury, has the patient been as interested in your sexual relationship and your responses and enjoyment?**
No change A bit less Much less

62. **Has the patient been taking the same interest in the children as before the injury?**
No change A bit less Much less

**Thankyou for your help**

Hospital Letterhead

Extension Number

Date

Dear ,

You may remember that I came to see you after you got home from Astley Ainslie Hospital about a year ago. As part of that project we are keen to see how things are for people in the first year or so after the sort of illness/injury you had.

If possible, I would like to see you, and a member of your family again to discuss how things are going.

I will visit you at home on _____ __/__/__ at _____

If this is not a suitable time, please just contact me and we can arrange another.

Yours sincerely,

Kath McPherson
Registered Nurse

Hospital Letterhead

Extension Number

Date

Dear ,

When you were in Astley Ainslie Hospital, we arranged that I would visit about five weeks after you left hospital. This visit is part of a study we are doing to see how things have been for you since leaving hospital.

If possible I would also like to speak with a member of your family as this gives an opportunity for them to raise concerns or ask any questions they may have.

I will visit you at home on _____ __/__/__ at _____

If this is not suitable please just contact me and we can arrange another time.

Yours sincerely,

Kath McPherson
Registered Nurse

**Astley Ainslie Hospital**
**Charles Bell Pavilion**
**ph 0131 557-9233**

## Outcome after Head Injury or Haemorrhage

### Information for Patients

After someone has been in hospital for a number of weeks or months, going home is the next challenge. We are keen to find out how best to help things go smoothly when people go home after a brain injury. As part of this, we would like to see you at home in the few weeks after discharge from hospital. This gives you and your family an opportunity to ask any questions you might have, and also helps us to see if there are other ways we might provide support or information.

It is also important to know if this sort of visit is helpful to you or your family. In order to find this out, we are doing a project where we would like to ask your view about your health or any concerns at about six weeks after discharge and then again after a year.

You are under no obligation to take part in the study and can decide at any time to withdraw. If you agree to take part, we would like you, (and if possible a family member) to complete a questionnaire.

Any information you give will be treated in strict confidence and will not affect any medical treatment you are having. If there is anything that I feel might be helped by further care, I would ask your permission to mention this to your GP or the consultant in charge of your care.

If you have any questions about this project, please feel free to phone me at the above number. If you have any concerns about being in the project that you would like to raise with someone other than myself, Mrs Jane Miller (Clinical Services Manager at Astley Ainsle Hospital ph 557-9000) may be contacted.

Kath McPherson
(Registered Nurse)

**Consent Form**

I agree to take part in a project looking at the how a brain injury effects the health of the person who has had the injury, and on the family. The project has been explained to me and I have had an opportunity to ask questions about the project.

I agree for my GP to be told that I am taking part in the study, and that any information that is important to my health will be passed on to him/her or the consultant in charge of my care in hospital. Otherwise all information will be treated as strictly confidential and my name withheld in any discussion of the results of the study.

I understand that I am not under any obligation to take part in this project and can withdraw at any time. I also understand that neither taking part in the project or refusing to, will alter the treatment I would normally receive.

Name _____ _____ (Patient/Spouse/Parent)

Signature _____

Signature of Researcher __ _____ Date ____ _____

OUR REF: YOUR REF:

1702/ 94/4/37.
R A Robertson, Ext. 5607
14 April, 1994

Dr B Pentland
Charles Bell Pavilion
Astley Ainslie Hospital

Dear Dr Pentland,

**REQUEST FOR ETHICAL APPROVAL - "Functional outcome after brain injury"**

Thank you for submitting the above protocol for ethical approval. The Medicine & Clinical Oncology Research Ethics Sub-Committee has considered this protocol and has granted ethical approval.

Under the terms of the Scottish Office Home and Health Department Guidelines on Local Research Ethics Committees this decision has been notified to the NHS body under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Research Ethics Sub-Committee.

A condition of this approval is that you are required to notify the Sub-Committee, in advance, of any significant proposed deviation from the original protocol. Reports to the Sub-Committee are also required once the research is underway if there are any unusual or unexpected results which raise questions about the safety of the research.

In addition, researchers are required to report on success, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the project among patients and volunteers.

Yours sincerely,

R A Robertson
Secretary
Medicine & Clinical Oncology
Research Ethics Sub-Committee

Appendix (ix) - Ethical Approval
AAA

13 APR 1994

148 PLEASANCE EDINBURGH EH8 9RS
TELEPHONE: 031 668 3940 FACSIMILE: 031 668 3953

Please quote the above reference on all correspondence

**Questionnaire to Evaluate Outreach Nurse Visits**

The following questions are designed to find out your opinion of the service you received from (Name of Worker). Can you please read each question and answer by ticking the box that best fits your answer. (If you would like to, please write any additional comments as you go through the questionnaire).

PLEASE TICK A BOX FOR EACH QUESTION

1. The first question is about the number of contacts KM had with you during the first few weeks after discharge from hospital.

   How many visits did you receive?

   Too many ☐
   Enough ☐
   Not enough ☐
   Not Applicable - contacts were by phone ☐

2. In general terms, how helpful were the contacts (phone or visits)?

   Not at all helpful ☐
   Not very helpful ☐
   Quite helpful ☐
   Very helpful ☐

3. Did you receive assistance from KM on concerns you had?

   None at all ☐
   Some ☐
   Help with all concerns ☐
   We had no questions or concerns ☐

4. How helpful was the information and advice from KM?

   Very helpful ☐
   Quite helpful ☐
   Not very helpful ☐
   Not at all helpful ☐
   We received no information or advice ☐

5. Taking everything into consideration, how satisfied were you with the contact you had with KM?

   Very satisfied ☐
   Fairly satisfied ☐
   Not very satisfied ☐
   Dissatisfied ☐

6. Taking everything into consideration, do you think the visits you received made any difference after discharge from hospital?

It made things worse
It made no difference
It made things better

7. Was there any information or assistance that was particularly helpful to the person who had been in hospital? If so, could you write it in the space below.

8. Was there any information or assistance that was particularly helpful to you as family member or carer of the person who had been in hospital? If so, could you write it in the space below.

9. Please describe any aspects of the service you were not satisfied with.

10. If this service is to be offered to other people in the future, do you have any suggestions to improve it? Please describe these in the space below.

11. Please make any other comments in the space below.

THANK YOU FOR YOUR HELP

**Feedback on Intervention Project**

**Profession / Department** _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

**(Please tick the box that fits your opinion best and add any comments)**

From your experience, have their been **any benefits** from the intervention by Name?

- none at all ☐
- not many ☐
- some ☐
- many ☐

If you feel there have been **benefits**, please describe them:

From your experience, have their been **any negative effects** from the intervention by Name?

- none at all ☐
- not many ☐
- some ☐
- many ☐

If you feel there have been **negative effects**, please describe them:

Did the intervention by Name, **assist** your management or treatment of patients

- not at all ☐
- infrequently ☐
- occasionally ☐
- frequently ☐

Did the intervention by Name, **interfere** with your management or treatment in any way?

- not at all ☐
- infrequently ☐
- occasionally ☐
- frequently ☐

Please use the space below for any other comments you would like to make regarding the project.

**Thankyou for your help**

**Selection of comments from users of the Outreach Nurse Service**

**Carers**

'It was really useful to get tips on how to deal with difficult situations that arise between carer and cared for. They also helped the rest of the family. KM was a very caring and good listener. I appreciated the service as a link between hospital and home - just before leaving hospital - so many things are going on that you don't always take everything in - the visits helped'

'Helped us understand the co-ordination of services and how to raise issues of concern with various professionals - making the link between hospital and community. The meetings between us together with our son and KM were particularly helpful in dealing with areas of conflict. KM's skills in helping x let down his defenses and listen and move on were of a high order e.g. talking about his epilepsy.'

'I'm a bit confused between the role of the social worker and KM … x's rehabilitation at home was greatly aided by the emotional and practical support, advice and information which KM was able to provide to us. Very helpful to have one person with the time to listen and to fit in with our programme.'

'Everyone should have this service for 5-6 weeks after discharge - so much is unpredictable - so many anxieties - weekly visits helped to deal with much of these and avoid crisis.'

'KM was most helpful and it was very reassuring to know that if things had not gone as well as they did after my daughter's accident, that there was someone who we could turn to for help and reassurance.'

'It's difficult to speak for other people as I have coped very well - I think for people who need it, KM would be a great help but I have been lucky with x as he is still the same person he has always been - it was good for x to hear how to plan his day as he would overdo it at first and that would tire him out.'

'I think the carer should be told more of what to expect when the patient comes home meaning about mood swings and other things to do with behaviour. This is not a criticism for I have nothing but praise for all the staff - they were kindness in itself.'

'KM quickly became someone we felt at ease with when discussing our feelings - much more than say in a hospital appointment or 10 minutes at the GP.'

'It was really helpful to discuss things like Information about things like epilepsy and how to cope if someone has a fit.'

'I think if it were not for KM - I would not have taken the strain - she helped - especially because it took a while for things to get going once x came home.'

'There were a few questions relating to x's injuries that we felt were not answered while he was in hospital. KM put our minds at rest after she had explained them all to us.'

'I found Kath very easy to talk to and looked forward to her visits. She gave me confidence and I felt she knew more about my case than my doctors would. I felt free to ask questions and my husband and I were both sorry when her visits stopped although there were probably enough visits'

'It made sense that recovery would be gradual - each set back was in a way normal and to be expected'

'Advising me how to plan my day - getting up at a reasonable time was helpful - felt I could see I was getting better'

'She didn't speak to me like I was a just a kid - that made a difference'

'When a family goes though a trauma like ours, it helps a great deal when you have someone to help you through it when the patient comes home. '

'Sometimes carers assume a greater degree of connection between professionals than actually exists - it helps to have someone to co-ordinate things.'

**Selection of comments from colleagues about the Outreach Nurse Service**

'Improved communication, collaboration and co-ordination. This has shown itself to be an invaluable service, it should be reviewed and proposals for its development discussed.' *Psychologist 1*

'The problem of brain injury, its effects and treatment is one of the areas where community O.T's in common with General Practitioner have difficulty in keeping up to date. The ready availability of specialist workers to bridge the gap between hospital and home is of great assistance in ongoing care and realistic expectations.' *Community Occupational Therapist (OT)*

'Reinforcement of information given to people in their own home. Contact/good relationships with relatives or carers. Able to monitor if people are able to do/continue with home programmes.' ***Hospital based OT***

'It is very useful to have an identified contact person within the hospital. Also, KM has been very flexible in her approach and is prepared to respond to other workers' concerns (mine anyway!) It is very helpful to have another perspective from a person with her clinical expertise but who is open to another worker's approach.' *Community Organisation*

'The people I have had contact with who see KM have been positive about her involvement. She seems very sensitive to the continuing difficulties that individuals can have. I feel it is important that there is recognition from the hospital that people's needs for information , consultation and support continues beyond immediate rehabilitation phase.' *Community Organisation*

'Contact with patients and carers especially after discharge. Information. Important role, needs to develop in a local basis as well.' *Medic*

'Greater expertise in brain injury than I can have in a mixed case load gives me and certainly the family a greater feeling of confidence and less of a feeling of panic and abandonment at home.' *Community OT*

'People often speak very negatively about hospital experiences and very positively about involvement with KM. Carers and service users have spoken about feeling very supported, people who we meet who have not received this service seem not to feel at all supported. We also have found the project useful because it has referred people to us for whom we've been an appropriate resource.' *Community Organisation*

Some patients feel overwhelmed by the number of people involved post discharge and that they are asked the same questions again and again. I feel however, that the benefits gained from your intervention greatly outweigh the occasional negative effect of the involvement of yet another professional!! Our service has found this a very useful project and we are hoping to establish our won outreach worker.' *Medic*

'Allowed for feedback from the hospital, Helped give a clearer picture of what was planned - gave a specific person to contact. Client was often more accepting of advice/instruction from a hospital based service - it helped reinforce work we were doing.' *Community OT*

'No interference with my management due to good communication by KM about what she was doing and what she had discussed with patients and relatives. The Outreach Nurse is now a valuable member of the outpatient team. The post should definitely be developed into a full-time role to allow for the intervention which is obviously required.' ***Hospital based OT***

'Good contact for family liaison especially if difficulties have been encountered. Good for referrals to other services, eg Headway Stroke support Services etc.' ***Hospital based Physiotherapist***

'Patients may rely excessively or become somewhat dependent on hospital service ... Professionals also tend to depend on the service and I have some concern about service in the absence of KM (When on leave, when the project finishes). I have a feeling that GPs are so far not tightly included in outpatients care programme and their voices are not heard - is this an additional role for the outreach nurse?' *Medic*

'Provides a focus for the patient/family in regard to treatment, goals, problem solving. Helpful to know how patient is performing at home. This may not be a negative effect, but perhaps in the past patients may have been referred to a day service, but more appropriate assistance is now sought through the outreach worker.' *Hospital Based Daycare*

## Publications directly associated with this thesis

**Papers**

McPherson, K.M., Berry, A. and Pentland, B. (1997) Relationship between cognitive impairments and functional performance after brain injury, as measured by the Functional Assessment measure (FIM+FAM). *Neuropsychological Rehabilitation, 7(3), 241-257*

McPherson, K.M. and Pentland, B. (1997) Disability in patients following traumatic brain injury - which measure? *International Journal of Rehabilitation Research, 20(1), 1-10*

McPherson, K.M. Pentland, B., Cudmore, S.F. et al (1996) An inter-rater reliability study of the Functional Assessment Measure (FIM+FAM). *Disability and Rehabilitation, 18(7), 341-247*

McPherson, K.M. and Pentland, B.(1994) An attempt to measure the effectiveness of early brain injury rehabilitation. *Health Bulletin, 52(6), 438-445*

**Presentations at Scientific Meetings**

McPherson, K.M. and Pentland, B. Information for carers following inpatient brain injury rehabilitation. *2nd World Congress on Brain Injury, Seville, May 1997*

McPherson, K.M. and Pentland, B. Measurement of outcome in early rehabilitation. *J Douglas Miller Memorial Meeting, Edinburgh, October 1996*

McPherson, K.M. and Pentland, B. Perceived health in carers of people with brain injury. *1st World Conference in Neurological Rehabilitation, Newcastle, June 1996 European Journal of Neurology 3: Supp 2, 56*

Cudmore, S.F. and McPherson, K.M. Multidisciplinary assessment of disability. *2nd Leeds Neuro-rehabilitation Conference, Leeds, Sept 1995*

McPherson, K.M. Pentland, B. and Cudmore, S.F. Assessing disability following brain injury. *1st World Congress on Brain Injury, Copenhagen, May 1995*

McPherson, K.M. and Pentland, B. Is comprehensive monitoring of brain injury recovery possible. *British Psychological Society Proceedings 1994, 2(2) 58*

McPherson, K.M., Pentland, B. and Berry, A. Is comprehensive monitoring of brain injury recovery possible. *Society for Research and Rehabilitation, Newcastle, January 1994, Clinical Rehabilitation, 8(3), 273-274*